Medicines Management after Hospital Discharge: Patients' Personal and Professional Networks

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Abstract

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Keywords: Patient safety; medicines management; hospital discharge; social network analysis; medications; care transitions; human factors.

Improving the safety of medicines management when people leave hospital is an international priority. There is evidence that poor co-ordination of medicines between providers can cause preventable harm to patients, yet there is insufficient evidence of the structure and function of the medicines management system that patients experience. This research used a mixed-methods social network analysis to determine the structure, content and function of that system as experienced by patients. Patients' networks comprised a range of loosely connected healthcare professionals in different organisations and informal, personal contacts. Networks performed multiple functions, including health condition management, and orienting patients concerning their medicines. Some patients experienced safety incidents as a function of their networks. Staff discharging patients from hospital were also observed. Contributory factors that were found to risk the safety of patients' discharge with medicines included active failures, individual factors and local working conditions. System defences involving staff and patients were also observed. The study identified how patients often co-ordinated a system that lacked personalisation and there is a need to provide more consistent support for patients' self-management of medicines after they leave hospital. This could be achieved through interventions that include patients' informal contacts in supporting their medicines use, enhancing their resilience to preventable harm, and developing and testing the role of a 'medicines key worker' in safely managing the transfer of care. The role of GP practices in co-ordinating the involvement of multiple professionals in patient polypharmacy needs to be further explored.

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And to Tudor Gwynn, diolch yn fawr fy nghariad.

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Glossary of Terms

Actor
An individual (a patient or a contact of a patient).

Adverse Drug Event (ADE)
Injury of harm resulting from the use of medicine.

Adherence
The extent to which people take their medicines as they are prescribed.

Alter
Another individual present in the ego's network.

Betweenness
A measure of the extent to which an actor connects other actors.

Broker
An individual who connects other individuals to each other.

Cardiac rehabilitation nurse
A specialist nurse providing care for people with cardiac disease to help them achieve optimal health.

Care setting
The place where care is delivered to a patient, including a hospital, a GP surgery, or a patient's own home.

Care transfer
The change in responsibility for the patient's healthcare between care providers or care settings.

Community pharmacist
A pharmacist offering services to patients in the community.

Degree
The number of ties of one individual.

Density
A measure of the proportion of connections in the network.

Discharge
The point at which a patient leaves hospital to retune home or to a different care setting.

Discharge summary
A clinical report written by a doctor or other healthcare professional when the patient is ready to leave hospital. Discharge summaries usually contain information about the reason the patient was admitted, the care received, changes to medicines and instructions about follow-up care.

Dyad
Two individuals who are connected.

Ego-network
The personal network of one individual (patient).

Ego
The individual (patient) who is the focus of interest.

General practitioner (GP)
A community-based doctor providing general treatment to patients.

Handover
The transfer of responsibility for care between healthcare professionals.

Hand-off
A communications that transfers responsibility for care between individuals or organisations.

Health and Social Care Information Centre (HSCIC)
A UK executive non-departmental public body that is the national provider of information, data and IT systems in health and social care.

Healthcare professional (HCP)
A qualified or trained person authorised to and currently delivering healthcare. Examples include doctors, nurses, and community pharmacists.

Heart failure nurse
A specialist nurse providing care for people with heart failure.

Homophily
The similarity between actors in a network.

Latent failure
Failure in an organisation that may create risk to patients.

Medication error
Mistakes in the prescribing, dispensing, administration or monitoring of a medicine.

Medicines Use Review (MUR)
A service offered by pharmacies in the UK for patients to discuss their medicines with a community pharmacist.

National Institute for Health and Care Excellence (NICE)
A UK Department of Health sponsored body that provides guidelines for the acre of patients.

National Patient Safety Agency (NPSA)
Department of Health body set up to improve the safety of healthcare provided in the UK (disbanded in 2012).

New Medicines Service (NMS)
A community-based service delivered by community pharmacists that support people who are newly prescribed a medicine for a long-term condition.

Policy
A set of principles to guide decisions and specify procedures.

Primary care
Healthcare received by patients in their local area comprising GPs, practice nurses, community pharmacists, optometrists, dentists and NHS walk-in centres.

Secondary care
Planned or unplanned healthcare delivered in hospital.

Sociogram
A visualisation of the network showing individuals and the connections between them.

System
A set of procedures and circumstances dictating how something is done.

Ties
Connections between individuals.

TTOs
To-take-out medicines which are given to the patient at the end of their stay in hospital.

List of Abbreviations

ACE	Angiotensin Converting Enzyme
ADE	Adverse Drug Event
AIDS	Acquired Immune Deficiency Syndrome
ARB	Angiotensin Receptor Blocker
COPD	Chronic Obstructive Pulmonary Disease
CQC	Care Quality Commission
GP	General Practitioner
GTN	Glyceryl Trinitrate
HCP	Healthcare Professional
HMPS	Harvard Medical Practice Study
HSCIC	Health and Social Care Information Centre
IMD	Index of Multiple Deprivation
MES	Medicine Experience Scale
MUR	Medicines Use Review
NHS	National Health Service
NICE	National Institute for Health and Care Excellence
NMS	New Medicines Service
NPC	National Prescribing Centre
NPSA	National Patient Safety Agency
NRLS	National Reporting and Learning System
PSNC	Pharmaceutical Services Negotiating Committee
RPS	Royal Pharmaceutical Society
SNA	Social network Analysis
TTOs	To-take-out medicines
UK	United Kingdom of Great Britain and Northern Ireland
USA	United States of America
WHO	The World Health Organisation
YCFF	Yorkshire Contributory Factors Framework

Chapter 1 – Introduction

1 Background

Maintaining patient safety when healthcare is transferred between providers is recognised as an international priority. People, especially those with complicated healthcare needs such as multiple morbidities, are at risk during care transfers because care is delivered by different providers who may not effectively co-ordinate and because patients may not receive the information, help and support they need. Within the UK NHS, for example, people receive healthcare from different organisations at different times according to their needs. Their care may be provided by a hospital when they need emergency treatment or the care of specialist clinicians, and when they leave hospital, care is usually transferred from an acute NHS trust to an NHS primary care team (usually the GP-led team). Discharge information about their treatment and recommendations for future care should be communicated to the patient and to the primary care team managing their ongoing healthcare needs. This information includes their current medicines list, which may have been changed by the hospital team, along with any recommendations for how their medicines should be managed. Patients are at risk during this transfer because discharge medicines information can be poorly managed or inaccurate and patients may have new or changed medicines that they do not understand or feel confident about using.

A range of healthcare professionals (HCPs) perform roles supporting discharged patients' medicines use, including GPs, nurses, community pharmacists and administrative teams. Patients may also have follow-up out-patient treatment provided by the hospital and additional appointments with specialist healthcare providers managing any other chronic conditions.

This thesis aims to explore and appraise patients’ experiences of the healthcare they receive specifically relating to their medicines from the point of hospital discharge, examining the structure and function of the medicines management system. In doing so, it will also identify the risks to patient safety in the system and how they impact on patients.

This work employs novel methods through the application of Social Network Analysis to explore how patients experience the system of medicines management and its contribution to patient safety and the effective use of medicines. Specifically it addresses the following objectives:

- To determine the structure of the discharge medicines management system from patients' perspectives;
- To understand how patients' medicines are optimised from the point of hospital discharge;
- To examine how safe the discharge medicines management system is for patients.

The following sections will explore the underpinning theories, research approaches and policies relevant to this thesis. To begin, the topic of patient safety is discussed and its rise in prominence across international and UK healthcare.

1.1 Patient safety

This section provides a concise background to the concept of patient safety both internationally and in the UK, initially considering the various definitions of patient safety in the literature.

Patient safety is the reduction in preventable harm in healthcare;[1,2] a series of processes to reduce error and mitigate risk;[3,4] an attribute of a system of care; [4–6] and a healthcare discipline.[6] Any outcome of harm which has arisen from the care provided is generally known as an 'adverse event',[1] which is an injury caused by the care provided rather than by the patient's health condition. These can be caused by failure to provide suitable care (omission) or by care that causes harm (commission).[1]

In the early 1990s in the USA, the Harvard Medical Practice Study (HMPS) aimed to estimate the incidence of adverse events experienced by patients in hospital.[7,8] The first large-scale epidemiology of patient safety, its team reviewed over 30,000 case notes from 51 hospitals. The first published paper from the study calculated a 3.7% incidence of adverse events due to diagnostic errors and negligence; the second reported that drug complications were the most common type of harm caused to patients in hospital (19%), followed by wound infections (14%). Since then, patient safety has been a growing

international priority in healthcare systems. Influenced by the findings of the HMPS, the landmark USA report *To Err is Human: Building a safer healthcare system* established the high level of death in the USA attributable to preventable harm in healthcare and how the fragmented healthcare system was a contributing factor to unsafe care.[9] The report laid bare the level of harm caused to patients; indeed, deaths due to error were thought to outstrip those attributable to diseases such as breast cancer and AIDS.

Since then, patient safety has become a priority for many governments and health services, leading to the establishment of different national bodies and organisations to lead research and policy initiatives, including the USA Agency for Healthcare Research and Quality (established in 1999), the Danish Society for Patient Safety (2001), the Canadian Patient Safety Institute (2003), and the Australian Commission on Safety and Quality in Healthcare (2006). Globally, the World Health Organization (WHO) made reducing patient harm a priority, launching its Patient Safety Programme in 2004. The WHO Patient Safety vision is that *'every patient receives safe healthcare every time, everywhere'*.[10] To achieve this, it co-ordinates a range of international programmes and policy initiatives including research initiatives, safety event classification frameworks and a range of guidance on solutions for specific risks, including communication during patient handovers,[11] and assuring medication accuracy at transitions of care.[12]

In the UK, the publication fifteen years ago of *An Organisation with a Memory* highlighted the number of preventable safety incidents that regularly occurred.[13] It detailed how approximately 10,000 patients each year experienced serious adverse reactions from medicines (which are harmful unintended effects experienced by a patient as a result of taking a medicine) and recommended a range of changes, including unifying reporting systems, changing and opening up organisational cultures and adopting a 'systems' way of thinking – one that looks at the system that processes and people operate within – rather than solely focusing on the individual when an error has occurred. This Department of Health publication also eventually led to the formation of the National Patient Safety Agency (NPSA); the publically funded, arms-length organisation that developed a UK definition of a patient-safety incident:

"Any unintended or unexpected incident which could have or did lead to harm for one or more patients receiving NHS care."[14(p9)]

This definition has since been adopted by NHS England as the NPSA was decommissioned in 2012 following a House of Commons Select Committee report in 2009. The UK government's response to *An Organisation with a Memory* was the 2001 report *Building a safer NHS for patients: implementing an organisation with a memory,* announced the establishment of the NPSA and plans for a new incident reporting and learning system, eventually leading to the establishment of the National Reporting and Learning System (NRLS) in 2003 to record and analyse patient safety-related events and compile a central database of patient safety incident reports. The Department for Health published further reports, notably *Building a Safer NHS for Patients: Improving Medication Safety*,[15] exploring the causes and frequency of medication errors and recommending action for the NPSA to take forward, including national standards of prescribing, dispensing and administering medicines.

Despite a continued focus on patient safety, progress has been slow. Indeed, work published in the last five years suggests that adverse events in hospitals continue to be greatly underestimated;[16] and that harm to patients is still common.[17] In the UK, the 2013 Francis Report documented the extremely poor standards of care experienced by some patients in Mid-Staffordshire NHS Foundation Trust.[18] The UK Prime Minister issued an official apology describing what had occurred as *"a national failure of the regulatory and supervisory system, which should have secured the quality and safety of patient care"*.[18(p12)] This official enquiry led to the Berwick Report into patient safety commissioned by the government, which clearly stated that individual staff members are rarely to blame for safety problems, rather the cause is usually the *"systems, procedures, conditions, environment and constraints"* faced by staff.[19(p4)] It recommended enhancing patient power and involvement at all levels of healthcare, sufficient current and future staffing, better patient safety training and a commitment to organisational learning. The Keogh Review, published in the same year, explored the quality of care provided by NHS trusts and foundation trusts with persistently high mortality rates.[20] The review developed a set of eight ambitions for the NHS, including: better uses of data to reduce preventable deaths; involving patients and the public as equal partners;

integration of trusts into the new Academic Health Science Networks; adequate staffing levels; and a happy, engaged, motivated and valued workforce.

Currently patient safety is firmly embedded in commissioning and governance structures.[21,22] Indeed, protecting patients from harm is now a specific NHS responsibility;[23] the most recent outcome framework for the NHS details key indicators around treating people in safe environments and protecting people from preventable harm.[24] Nested safety indicators to assess performance use reported patient safety incidents, incidents causing severe harm or death, hospital deaths caused by problems with care, and specifically the incidence of medication errors. The use of negative outcomes such as mortality rates is useful, however, as Reason argues, *"safety is a term more defined by its absence than its presence,"* and measures of the *"positive face of safety",*[25(p267)] such as the ability of the system to resist hazards might be better, more proactive indicators.

I have discussed how successive healthcare policy drives have advocated a systems way of thinking about patient safety in healthcare. The next section will focus on systems and specifically human factors.

1.1.1 Systems approaches to patient safety

This section discusses systems approaches to patient safety and how the human factors approach has been applied to exploring risks to patients in the healthcare system, understanding risk causation, and developing defences against errors. It begins with an overview of the science of human factors.

Human Factors

In 2000, the International Ergonomics Association adopted the following definition of human factors, which was seen as interchangeable with ergonomics:

"Ergonomics (or human factors) is the scientific discipline concerned with the understanding of interactions among humans and other elements of a system, and the profession that applies theory, principles, data, and other methods to design in order to optimize human well-being and overall system performance."[26]

According to the Human Factors and Ergonomics Society, a focus on Human

Factors arose during the second world war resulting from the work of specialists studying staffed systems. Their work focussed on systems performance, action control, workspace arrangements and skills requirements.[27] The results of their work resulted in, *inter alia,* safety improvements. Taking on board perspectives primarily from disciplines such as psychology and engineering, human factors is a multidisciplinary approach to explore how people and systems interact, for example, poor equipment design can lead to poor human use of equipment which may increase risk. Similarly, organisational factors, such as staffing levels, can place pressure on staff and influence the decisions they make within the workplace, leading to inappropriate and sometimes hazardous workarounds.

The WHO defines human factors slightly differently as: *"the study of all the factors that make it easier to do the work in the right way"*.[28] As a definition it does not explicitly recognise that there may be multiple perspectives on what the right way is to perform a task and that an organisation's policies and procedures may be perceived by staff as the right way but in fact may contribute towards risk.

More recently, Russ et al. argued that the science of human factors is primarily concerned with promoting efficiency, safety and effectiveness by improving systems to enhance their design for human use.[29] A central assumption in human factors is that people interact with systems in a complex and variable way. By accepting this, organisations can explore how systems and working conditions interact with human behaviour to create risk and take steps to mitigate those risks. Within the healthcare system, for example, factors combine to influence patient safety at organisational, immediate environment, team, individual and task levels, which in turn interact with external environmental factors and patient characteristics to create safety risks.[1,30]

This theoretical concept was described in James Reason's 1990 work on the breakdown of complex systems, in which he also explained that the individual actions of people – or the people themselves – are often the subject of scrutiny after incidents occur, yet they are rarely the direct cause. Instead it is the systems within which people operate that give rise to the conditions that allow safety incidents and major disasters to occur, especially in high risk industries

such as aeronautics and the travel industry.[31] Whilst this work focussed on major high-profile system breakdowns outside healthcare, later work shifted the focus to healthcare and adverse events in clinical practice, highlighting the two approaches to human fallibility: the person approach and the systems approach.[32] The person approach concentrates on and blames the actions of individuals, whilst the system approach recognises people's fallibility, the role of systems in organisational failure, that errors are inevitable, and that reliable organisations have well-constructed systems that avoid or can tolerate errors. The person approach is considered flawed because the person is judged to be separate to the system in which they operate, rather than an integral part of it. Reason outlined how systems have defences, barriers and safeguards that protect people from harm. If holes in those defences simultaneously align then this allows hazards to impact on people. In his 'Swiss Cheese' model (see Figure 1) he outlined how holes arise through 'active failures': slips and lapses; fumbles; procedural violations; and mistakes.

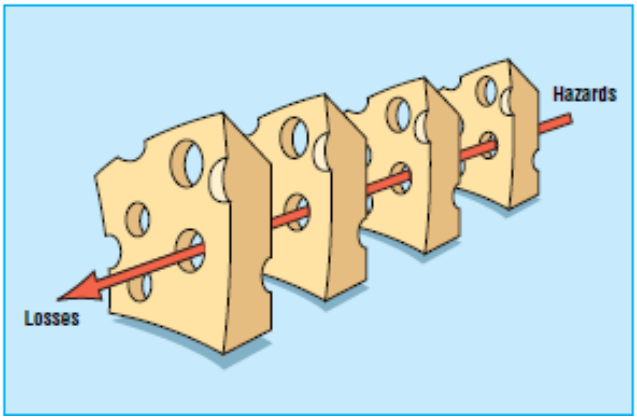


Figure 1: Reason's 2000 'Swiss Cheese' model of hazard trajectory.[32] Reproduced with kind permission.

Lapses, for example, are errors associated with forgetting to perform actions, slips and fumbles are errors that occur when a person performs an action but it is not the one they intended to perform. Mistakes are described as actions that are performed as intended but they are incorrectly planned. Violations are deliberate deviations from procedures, although sometimes a deviation may be unknowingly committed. 'Local conditions' such as the routine business of a ward are influenced by 'latent conditions' – those aspects of the system that create the conditions where it is easier for active failures to occur, such as staffing policies or inadequate training. Reason explains that latent conditions can exist in systems for long periods of time whilst essentially 'lying dormant'

until holes in defences align to allow a hazard to become a loss.[32] The central premise remains as the model has evolved, that latent conditions are not definitive causes but are essential for causal agents to have an impact.[25]

Whilst the human factors paradigm has been widely acknowledged as useful in developing organisational resilience in healthcare, patients have probably yet to recognise it or indeed understand it, and human factors does not focus on the roles patients play in healthcare systems. Patients are well positioned to make a strong contribution to understanding the cause of preventable harm and to building a more resilient healthcare system;[33,34] yet they are often characterised as passive recipients of care, as well as passive victims when things go wrong, rather than experts in their own health, well positioned to build resilience into the healthcare system by creating strategies to avoid error or mitigate its effects.[35] Indeed approaches to safety have underplayed the involvement of patients in setting safety agendas and engaging in safety initiatives.[36,37]

This section has focussed on the theory underlying a systems approach to patient safety in healthcare, and criticised it for its lack of focus on the role of the patient within healthcare systems. The following section will explore the issues that create risk for patients in the healthcare system when their care is transferred between clinicians and organisations. It will also discuss the inherent problems which may occur when patients are not a fully integrated part of the healthcare system and errors and discrepancies are considered at patient and system levels separately.[38,39]

1.1.2 Patient safety at transfers of care

A transfer of care is *"the movement of patients between health care practitioners, settings, and home as their condition and care needs change"*.[40(p3)] 'Gaps' in the continuity of care can be experienced by patients when their care is transferred and gaps are *"most readily seen when they are aligned with organisational and institutional boundaries that mark changes in responsibility or authority, different roles of professionals, or formal divisions of labour".*[41(p792)]

Transfers of care can take several forms. Care can be transferred within the same organisation where responsibility transfers between staff members, for example during a shift change or the transfer of a patient between wards or

departments. Care transfers also occur between organisations – from hospital to a nursing home, for example, or to a primary care team. When care transfers back to the GP-led team the patient will probably be returning to their home or to the home of a relative of friend and so there is usually no continuous direct observation of their condition by a HCP.

Hand-offs (which are communications that transfer responsibility for care) are complicated, poorly standardised, single- or multi-organisation events in patient care in which the responsibility for the patient is transferred either between individuals or organisations.[42,43] Handovers in care (or transfers of care from one clinician to another) are recognised as parts of the healthcare system where the risk of error is heightened.[44] Handovers also represent opportunities for corrective action, updating and correcting the patient's current list of medicines, and patient involvement, such as giving patients information about current medicines and who is now responsible for their care.[11,45]

In the USA, both 30-day re-admission rates after leaving hospital and the rate of adverse events after discharge are high (20%).[46,47] Specifically after discharge from hospital, patients have been found to experience adverse drug events;[48–51] and experience dissatisfaction with the care they receive.[52] Patients can also experience disorientation after their care is transferred: research has found that people, especially older people, experience anxiety and struggle to access information about their health and treatment.[53]

Concern about the safety of care transfers has led to a focus on what is referred to as 'transitional care', which is the care a patient receives when they move between care providers. Eric Coleman and Chad Boult, on behalf of the American Geriatrics Society define transitional care as:

"A set of actions designed to ensure the coordination and continuity of health care as patients transfer between different locations or different levels of care within the same location. Representative locations include (but are not limited to) hospitals, sub-acute and post-acute nursing facilities, the patient's home, primary and specialty care offices, and long-term care facilities. Transitional care is based on a comprehensive plan of care and the availability of health care practitioners who are well-trained in chronic care and have current information about the patient's goals, preferences, and clinical status. It includes

logistical arrangements, education of the patient and family, and coordination among the health professionals involved in the transition. Transitional care, which encompasses both the sending and the receiving aspects of the transfer, is essential for persons with complex care needs." [54(p556)]

A review of evidence into care-transfer interventions initiated by hospitals, specifically hospital discharge, indicated that bridging interventions to avoid adverse outcomes (which are those that include components delivered in-hospital and after discharge) have embraced different strategies including patient engagement, use of dedicated staff and better co-ordinated communication with other care providers. Those interventions using dedicated staff working with patients before and after discharge reduced re-admissions and visits to emergency care.[55] In the USA, a range of initiatives have attempted to improve patients' experiences of hospital discharge. For example, Project RED (Re-engineered Discharge) comprises a multi-disciplinary team intervention delivering an eleven-component discharge package, including:

- Making appointments for tests and follow-up of test results;
- Organising post-discharge services and equipment;
- Identifying correct medicines and organising for the patient to receive them;
- Resolving discrepancies between the discharge plan and national guidance;
- Teaching the patient about the discharge plan and their diagnosis;
- Communication of the discharge plan to primary care;
- A follow-up phone call.[56]

Evaluation indicated that the programme was successful in reducing readmission, increasing attendance at follow-up appointments and reducing costs.[56,57] Again in the USA, Coleman et al. developed the Care Transitions Intervention, which is a patient-led self-managed programme focussing on medicines self-management; a patient-centred health record; primary care follow-up; and increased knowledge of 'red-flags' that indicate health deterioration. Part of the intervention is a Care Transitions Measure which is 15-item survey instrument assessing preparation for care transitions.[58] Qualitative

research employed in developing the measure indicated that there were four transition content domains which patients considered important:

- Information transfer;
- Preparation for what to expect next;
- Support for self-management; and
- Encouragement to assert preferences.[58]

In general, however, care transfer interventions have been found to lack economic justification and to lack a focus on contextual factors that may impact on patients' ability to access health services, such as the availability of primary care once they have left hospital.[55] These contextual factors may also include the level of informal support at home.

This section has outlined the major issues in patient safety, and specifically how patient safety is threatened during the gaps in care that arise when patient care is transferred, especially when they are discharged from hospital. The following section will begin by discussing a particular system in healthcare, medicines management, and the risks to patient safety that are created by that system, despite its intended purpose to reduce risk.

1.2 Medicines management

This section discusses medicines management, and the models that exist to describe it. The definition of medicines management has evolved over time. Early definitions described it as a composite system involving processes and behaviours that ultimately result in specific ways of using medicines.[59] As such, medicines management is the system that ultimately influences patients' experiences with their medicines. Indeed, when effective, the system can achieve an improved patient experience and better health outcomes;[59,60] increased value in medicines expenditure; and reduce hospital admissions.[60]

The Medicines and Healthcare products Regulatory Agency definition, cited by the Nursing and Midwifery Council, tied patient safety and patient benefit firmly into medicines management:

"The clinical, cost-effective and safe use of medicines to ensure patients get the maximum benefit from the medicines they need, while at the same time minimising potential harm."[61(p4)]

More recently, The King's Fund offered a definition that linked medicines management to safety with an additional focus on value for money and an enhanced use of medicines by patients, thereby introducing the idea that patients themselves have a role in managing their medicines:

"Medicines management supports better and more cost-effective prescribing in primary care, as well as helping patients to manage medications better. Good medicines management can help to reduce the likelihood of medication errors and hence patient harm."[60(p10)]

However, relatively simple definitions of medicines management, such as the ones above, do not communicate the complicated, multi-professional, dynamic system that comprises different types of patients interacting with different healthcare professionals – doctors, pharmacists, health visitors, nurses – working across different sites and settings who adopt varying roles in supplying, monitoring and reviewing medicines. The healthcare professionals involved work for different organisations and belong to different professional groups with diverse proprietary processes, procedures, discourses and professional jurisdictions, norms and prejudices. Within this complicated environment patients who receive multiple medicines, who are often chronically ill and have multiple co-morbidities, will often self-manage their day-to-day medicines. As such, it is a *complex system* – one in which there are many interrelated components that impact on each other but cannot be explored in isolation;[62] and one that varies in different care settings – for example in the community and in hospitals – and for different medicines.

1.2.1 Medicines management models

As discussed, systems of medicines management are complex and so to better understand how they operate in different settings and to impose some standardisation, a number of models have been developed to describe and map their processes.

Avery et al. adopted a systems approach to explore medicines management but with a focus on the primary care system to identify the risks in the system that can produce adverse events.[63] Stages in this model were prescribing, dispensing, monitoring and review, and patient education and compliance. Systems failures included deficiencies in computerised warning systems,

inadequate inter-organisation communication, poor therapeutic knowledge dissemination, poor systems for repeat prescribing, organisation and training of staff and deficiencies in HCP-patient communication. They listed possible proximal causes of an adverse event including lack of medicines knowledge, slips and memory lapses. Figure 2 is the Avery et al. adaptation of Reason's 'swiss cheese' model describing risks in medicines management using the scenario of a patient request for a repeat prescription of a previously used medicines which is contra-indicated – it demonstrates how a specific risk in the system can penetrate multiple layers or barriers designed to prevent it.[63]

Building on this model, there is an opportunity to enhance the role the patient plays as a system barrier to create more resilience in the system. For example, enhanced patient knowledge of their medicines – those that are current and discontinued – may avoid the repeat prescription request and patients creating their own checklists of medicines may reduce the risk of them ordering a discontinued medicine.

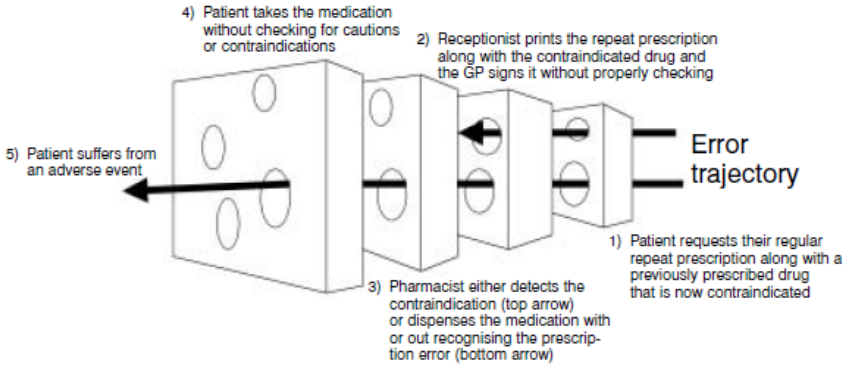


Figure 2: Avery et al. adaptation of Reason's 'swiss cheese' model to illustrate risk in medicines management.[63] Reproduced with kind permission.

Deeper integration of the pharmacist into the patient pathway, for example through discussing new medicines with the patient, would act as an earlier system barrier through increasing their understanding of and confidence in their medicines. There has been a growing acknowledgement that patients can play a meaningful role in their own safety if sensitively empowered to do so, despite both patient and clinician reservations about patient involvement in patient safety.[34] Patient vigilance, for example, can increase HCP compliance with safety measures in clinical settings, such as hand hygiene;[64] in medicines reconciliation following hospital discharge;[65] and in identifying problems with

medicines in primary care.[66] Furthermore, Furniss et al. recently explored how patients develop resilience strategies, such as developing cues to take medicines, such as alarms, to reduce the risk of unintentional non-adherence.[67]

The Swedish Lund Integrated Medicines Management Model for care transfers is a team-based approach that included clinical pharmacists performing medicines reconciliation and review functions to reduce medicines reconciliation errors and readmissions to hospital due to medicines errors.[68] Rather than being a universal medicines management model, it is an intervention to improve the medicines management of elderly people in hospital. It ends at discharge with medicines reconciliation and a discharge medicines report. The report, which details medicines changes and organises the medicines list by time of day, was found to reduce medication errors after discharge and the need for medical care caused by medication errors.[69,70]

Stowasser et al. mapped a universal medicines management pathway that is both independent of the care setting and the type of medicine.[71] The patient is involved at the different, largely interdependent stages, as shown in Figure 3 The patient ('consumer') is described as the focus of the pathway and interacts with its many stages. It is supported by three background processes: medicines procurement, reporting and quality and safety audit to monitor safety, and communication, which they describe as a vital process to keep patients informed about their treatment and to ensure information between healthcare providers is transferred accurately. The model is comprehensive yet, despite its central positioning of the patient, its focus falls on professional processes rather than on the patients themselves and as such it does not specify the patient-centred care now recommended.[72]

For example, keeping patients informed about their treatment falls short of current recommendations to give patients the opportunity to make informed decisions about their care. It also fails to communicate the range of professionals who are involved in the different stages and the multi-professional nature of many of the stages, for example in monitoring medicines, which may be done by doctors, pharmacists, nurses or a combination of all three. In Figure 4 I have developed Stowasser's model, drawing on current patient-centred approaches that take into account the patient's own preferences.[72]

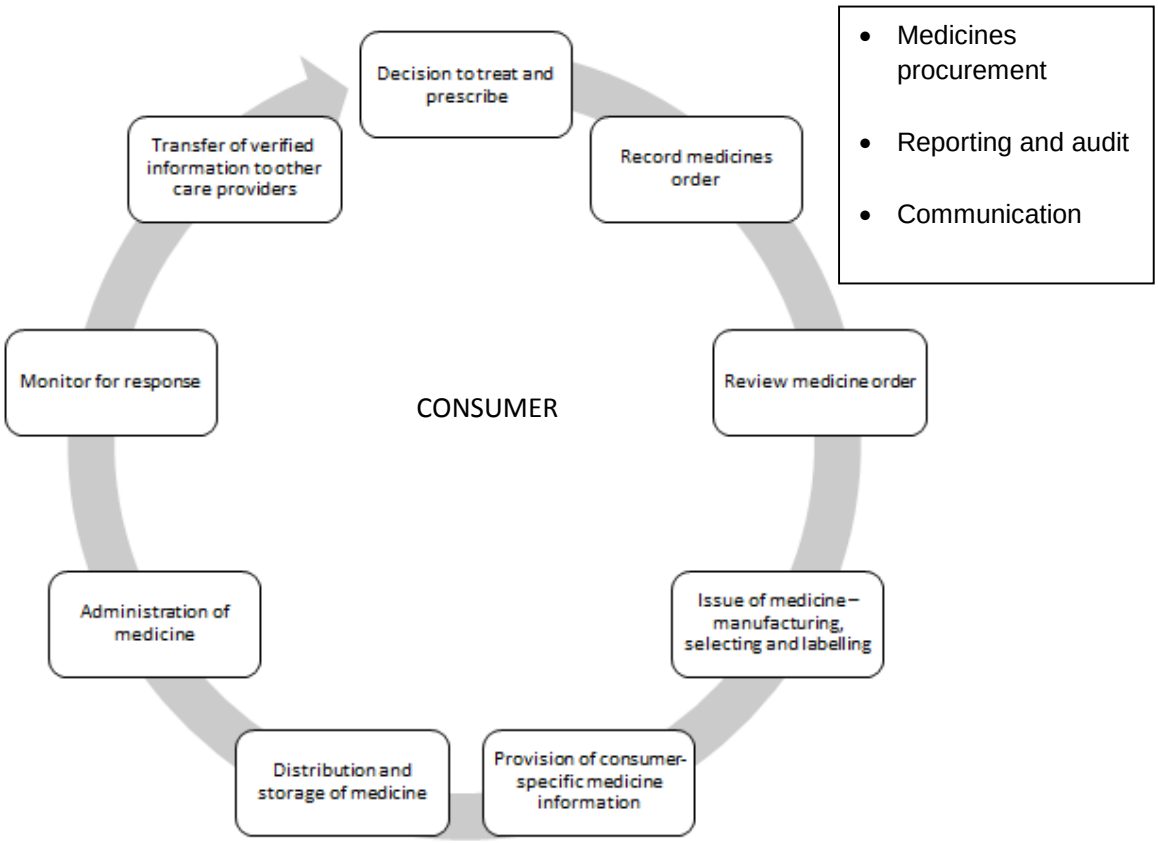


Figure 3: Medicines management model from Stowasser et al. [71]

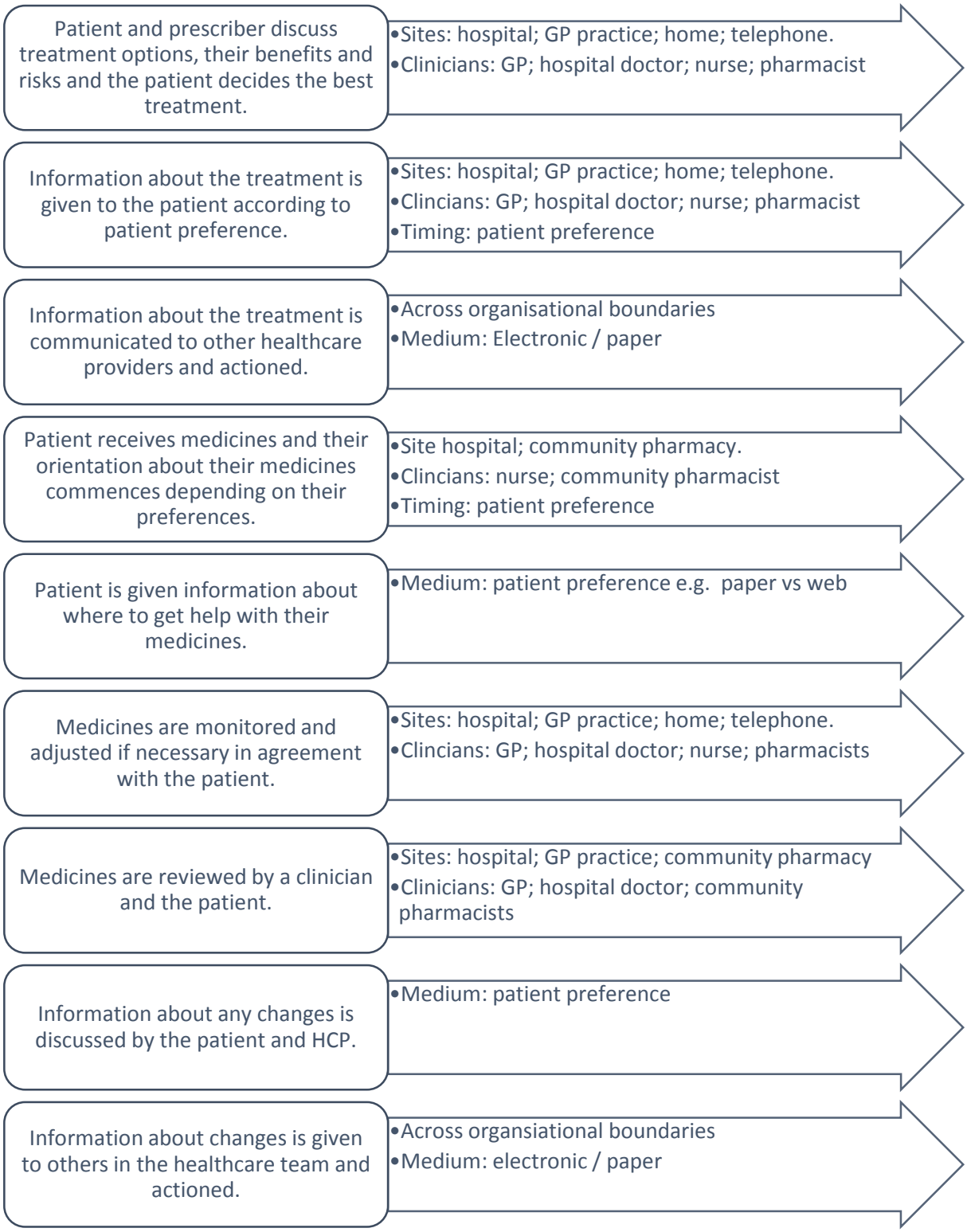


Figure 4: A patient-focussed adaptation of Stowasser et al.'s 2004 medicines management model.

1.2.2 Medicines optimisation

Medicines management has developed over time and organisations have attempted to offer definitions and articulate its role in the safety and quality of

care. However, medicines management has not been truly patient-centred – it has not focussed on patients as individuals nor taken into account their own preferences when defining care and role in its safety. In recognition of this, the term *medicines optimisation* has emerged in recent years as a patient-centred approach to medicines management, designed to achieve the best possible outcomes from medicines through their safe and effective use.[72] It is a multi-professional approach that involves patients in decisions about their treatment, but also one that encourages reporting of patient safety incidents concerning medicines, by both HCPs and by patients. Indeed, there is a growing recognition that the patient's role in reporting patient safety incidents is an *"untapped resource"*.[33(p698)]

In 2013 the Royal Pharmaceutical Society (RPS) issued best-practice guidance for medicines optimisation based on four key principles, which are shown in Figure 5.[73] It combines professional efficacy in the choice and safety of medicines with a focus on understanding the patient experience.

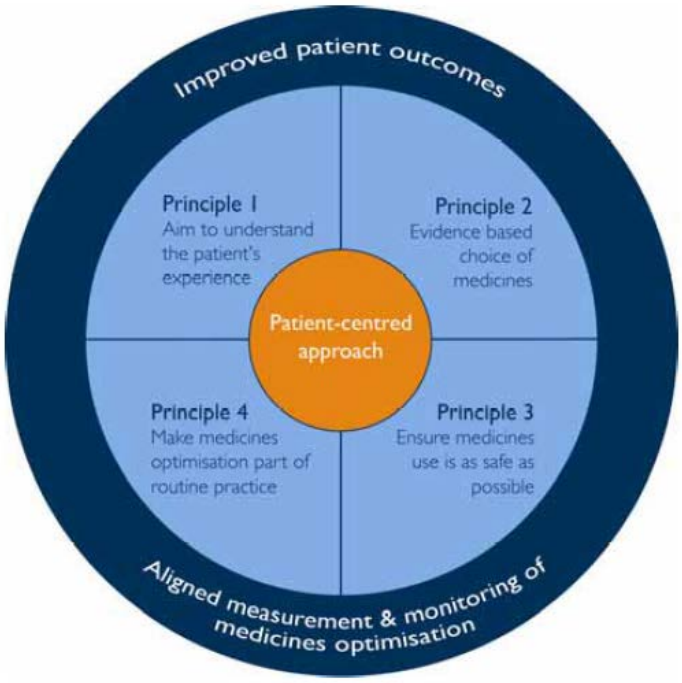


Figure 5: The RPS's four principles of medicines optimisation.[73] Reproduced with kind permission.

Medicines optimisation is an important underpinning policy and model of practice to the research described here because it combines the interrelated concepts of medicines safety, patient-centred care and medicines management systems. In this thesis, the concept of medicines optimisation has been used as

a foundation to explore patients' experiences with and roles in managing their medicines.

1.2.3 Preventable harm and risks in safe medicines management

Medicines management systems, which deliver and support people's use of medicines, are subject to risk. This section explores the epidemiology of medicines errors, some of the risks faced by patients in their use of medicines and the policies implemented to address those risks.

The Health and Social Care Information Centre (HSCIC) reported that in excess of 1000 million NHS prescriptions items were dispensed in the community in England in 2014 at a cost of £8.9 billion;[74] and the number of items dispensed has increased year-on-year and by over 50% since 2004. Patients increasingly manage polypharmacy (the concurrent use of several medicines); and organisations operating within the medicines management system must manage the clinical and administrative components that supply medicines to patients, monitor and review their use. Patients can consult different clinicians working within different healthcare organisations for different co-morbidities who may prescribe medicines concurrently. Within this complex system there are many opportunities for preventable harm to occur.

The WHO positioned medicines safety as an essential component of patient safety and recognised morbidity and mortality as a result of medicines errors as a major healthcare problem.[75] The NPSA calculated that preventable harm from medicines in England may cost in excess of £750 million each year.[14] At the time, the NPSA also believed that the incidence of medication error in primary care was under-reported because the volumes of reported incidents are low in relation to the proportion of medicines prescribed. This is a view that is still held today by policymakers,[72] supported by data from NRLS indicating that medication incident reports submitted by primary care organisations have continued to be comparatively low since reporting began in 2005.[76]

Reflecting the definition of a patient safety incident in section 1.1, medication error has been defined as "*a failure in the treatment process that leads to, or has the potential to lead to, harm to the patient*".[77(p601)] The range of errors patients experience include inappropriate or ineffective prescribing *(prescribing error),* errors on the prescription *(prescription error),* errors made during

dispensing the drug such as providing the wrong label *(dispensing error),* and during monitoring, for example not adjusting medication when necessary.[78] *Administration errors* involve giving or taking the wrong medicines dose, or using the wrong administration route, or an incorrect frequency or duration. Responsibility for administering medicines usually transfers from clinical staff to the patient, a member of their family or a carer after discharge from hospital, so errors can be made which may be harder to detect and address. Errors are also made during the use of medicines and if that is in the patient's home then they are harder to detect and address – partly due to patient characteristics, such as personality (for example their attitudes towards medicines), and social factors (such as others who may influence them). Medicines errors have been classified as knowledge-based errors, rule-based errors, action-based errors (slips) and memory-based errors (lapses);[78] and as slips and lapses, knowledge- and rule-based mistakes, and violations (routine, optimising and necessary).[79]

Amongst the patient safety incidents that patients may experience during their care, experiencing medication error is relatively common. For example in the UK hospital setting, adverse drug events affected 7–10% of in-patients;[80,81] Sandars and Esmail estimated that prescribing and prescription errors occur in up to 11% of prescriptions;[82] and harm from medicines is thought to contribute to between 2.5–6.5% of hospital admissions.[83,84] A recent review of reports to NRLS assessed that over half a million medication incident reports from primary and secondary care over five years from 2005–2010 comprised 10% of reported patient safety incidents and 16% of those resulted in patient harm.[76] Reporting levels from the acute/hospital sector far outweighed those from primary care, which is probably explained by underreporting of incidents by the primary care sector.[14] Not all medication errors result in significant harm to patients; many may cause mild harm, which may also influence the rates at which they are reported. Indeed, degrees of harm from patient safety incidents are classified into five categories – from mild to death – by the WHO, as presented in Table 1.[85]

A further risk to well optimised medicines is poor patient adherence: intentional and unintentional non-adherence is estimated to affect 30-50% of patients in

primary care.[86] In their review Garfield et al. suggested that focusing on improving adherence – along with safety and effectiveness of medicines – had the most potential for improving the system to maximise the benefit to patients.[86] Recent policy suggests that to do this patients should be involved in decisions about their medicines, that communication with patients must be effective, and that patients' perceptions of their need for medicines, and their knowledge and concerns about their medicines should be regularly reviewed.[87]

Table 1: Degrees of harm caused by patient safety incidents from The WHO, 2010.[85]

None	Patient outcome is not symptomatic or no symptoms detected and no treatment is required.
Mild	Patient outcome is symptomatic, symptoms are mild, loss of function or harm is minimal or intermediate but short term, and no or minimal intervention (e.g. extra observation, investigation, review or minor treatment) is required.
Moderate	Patient outcome is symptomatic, requiring intervention (e.g. additional operative procedure; additional therapeutic treatment), an increased length of stay, or causing permanent or long term harm or loss of function.
Severe	Patient outcome is symptomatic, requiring life-saving intervention or major surgical/medical intervention, shortening life expectancy or causing major permanent or long term harm or loss of function.
Death	On balance of probabilities, death was caused or brought forward in the short term by the incident.

Various UK policy initiatives and guidance have aimed to improve medication safety as a means of enhancing patient safety overall.[14,15,88] Most recently, the NICE guidelines for medicines optimisation made recommendations for reducing medicines-related patient safety incidents in three key areas:

- Improving reporting systems with the aim of learning from medicines-related patient safety incidents. Recommendations within this area included HCPs explaining to patients how to identify and report incidents.
- Medicines reconciliation – which is the process of identifying a complete and accurate list of a patient's medicines through comparing lists, resolving discrepancies and changes. Recommendations by NICE included conducting medicines reconciliation in primary care for patients discharged from hospital as soon as possible. It also stated that there should be clear lines of responsibility for conducting medicines reconciliation, and that it should be carried out by a trained healthcare professional. Furthermore that patients, family members and carers should be involved where appropriate, although no guidance is given about when this might be appropriate.

- Medicines review – a structured medicines review with a clear purpose should be implemented for defined groups of patients (those on multiple medicines; those with chronic and long-term conditions; and older people). The review should be carried out by a pharmacist or another appropriate HCP.[72]

Whilst some of the recommendations in the NICE medicines optimisation guidelines are embedded in other policies, for example the 2009 NICE clinical guidelines on medicines adherence,[87] other recommendations designed to help patients with their medicines, for example the Medicines Use Review (MUR), may not always work as intended.[89] Section 1.2.5, therefore, will explore the role of community pharmacists in the medicines management system, exploring how they have been positioned to advance medicines optimisation through clinical practice**.** To begin, the next section explores the specific problems in the system of medicine management when patients' care is transferred.

1.2.4 Medicines management at the transfer of care

There are key responsibilities in and principles of safe care transfer, which include ensuring accurate and timely communication of medicines information and encouraging patients to be actively involved in managing their medicines when they move between care providers.[90–92] People whose care is transferred – for example when they are discharged from hospital – are subject to heightened risk of harm from their medicines if information sharing between GPs and hospitals is poor, if patient records are not updated with discharge information and if patients do not get the opportunity to discuss managing their medicines.[91] The lack of a definitive list of medicines can lead to discrepancies between those lists held by different care providers and the medicines that the patient actually takes when they are discharged.[39,93–95] Patients can also experience unintentional discrepancies in repeat medication: 43-60% items and affecting 57% of patients;[86] although a 2014 literature review estimated that these discrepancies affect 14–87% of patients.[96]

Communication between hospitals and primary care has been found inadequate, for example in the poor quality, level of detail and timeliness of discharge, and can potentially lead to prescribing errors.[97,98] The Avery et al. study exploring the prevalence and causes of prescribing error in general

practice identified discrepancies in the post-discharge subsequent prescriptions of 43% of patients who had been discharged from hospital; however the small sample size for this part of the much wider study was small (n=37). Other evidence concurs that discharge information can be inaccurate or badly timed or GP practices can be slow to act upon it; [91,98–100] and, on discharge, patients are likely to have new medicines to which they may become non-adherent,[101,102] which can lead to sub-optimal outcomes, including readmission to hospital.[49] For other patients, medicines temporarily discontinued in hospital are not re-instated after discharge.[103]

Evidence from the international literature describing interventions to optimise continuity in medicines management was synthesised by Spinewine et al. in a systematic review.[104] The target of the interventions ranged from those aiming to educate and counsel patients both before and after discharge, interventions to enhance communication between providers and interventions aimed at both patients and providers. The authors concluded that there is some evidence of effectiveness for interventions aimed at reducing adverse drug events and hospital re-admissions comprising patient education and counselling before discharge, and reinforced after discharge, some of which included enhanced provider communication.

However, in the UK, lack of successful working between HCPs from different disciplines involved in care is recognised as a risk to safe use of medicines by both the Royal College of General Practitioners and the RPS.[105] To mitigate the risk to patients this poses, there is an increasing drive for more focussed and consistent interprofessional collaboration for safe and effective care.[73,105]

UK policy now champions the patient's role in medicines optimisation and safety during care transfers.[72,73] However, the most recent NICE recommendations do not specify how patients should be informed about their medicines when they are discharged, despite the comparatively detailed recommendations about how HCPs should communicate with each other.

Also thought crucial by the WHO is involving patients and their families in multiple ways, including: medicines education; giving patients information about new and changed medicines; patients keeping lists of prescription and over-the-counter medicines; and the use of one community

pharmacy provider.[106] The WHO suggested developing a standardised form for the patient to carry lists of their medicines, however in principle this would need to be backed up by other central systems to ensure information remained available to HCPs in instances where the patient is unable to provide their list, for example when accessing emergency care, or if they become incapacitated. As yet there is a lack of evidence of the benefit of such patient-held records.[107]

In 2005, collaboration between pharmacy bodies in England produced a guidance document about moving patients safely between care providers. *Moving patients, Moving Medicines, Moving Safely: Guidance on Discharge and Transfer Planning* mapped the weaknesses in medicines management when patient care is transferred between providers.[92] Identified risks to patients at discharge were the failure to inform the patient's GP of changes to medicines, lack of time at discharge to inform patients about their medicines, double dosing after discharge due to the patients having new and pre-admission supplies, poor patient understanding of medicines, intentional and unintentional adherence, and the continuation of medicines that were intended as a short course. The guidance unfortunately does not highlight the community pharmacist's role in supporting the patient's use of their medicines in this period. This role in patient care after hospital discharged is discussed further in the next section.

1.2.5 Community pharmacy medicines management role

Recognition of the risks patients have faced has led to exploration of the roles that community pharmacy can play in the more effective management of medicines. This section explores the policies that have attempted to redefine the role of community pharmacy within the medicines management system.

Community pharmacists are an established part of the multi-professional primary care team and, as such, have a key role to play in delivering safe care to patients, a role previously defined as providing 'pharmaceutical care' to the patient.[108,109]

In recent years, successive UK government policy initiatives have attempted to move community pharmacy towards a more meaningful and integrated role in safe and effective patient care. The 2003 Department for Health discussion paper *A vision for pharmacy in the new NHS* outlined ten key pharmacy roles.[88]

Amongst them were promoting patient safety by avoiding, detecting and reporting adverse drug reactions and medication errors, contributing to seamless, safe medicines management and supporting patients as partners in medicines taking. The paper emphasised pharmacy's importance in safe medicines use and maximising the benefit gained from medicine and reducing waste. The following Community Pharmacy Contractual Framework contained several elements to implement this policy, for example the introduction of MURs, explored in more detail later in this section.[110] The most recent Community Pharmacy Contractual Framework further developed these guidelines, formalising the alignment of target groups for the MUR more closely with NHS health priorities.[111,112]

Plans for pharmacy teams to improve the care patients receive through personalised pharmaceutical services were outlined five years after the publication of *A vision for pharmacy in the new NHS* in the 2008 Department of Health White Paper *Pharmacy in England: building on strengths, delivering the future*.[113] It set out how patient care could be made safer by integrating pharmacists in healthcare delivery, thereby developing their role in offering clinical services to patients in the community. Improvements championed in the paper included promoting better access to medicines expertise provided by pharmacists so that pharmacy teams lead and support safe and effective medicines use. It envisaged an enhanced role in supporting use of new medicines for patients with chronic conditions, and closer pharmacy involvement in developing clinical pathways in support of integrated care. It stressed that the risks of medicines-related harm can be mitigated by community pharmacists through various measures including:

- Working with and training others about safe prescribing and safe medicines use;
- Working with patients to enhance their medicines understanding; reviewing medicines use;
- Screening prescriptions and identifying adverse drug events; documenting allergies;
- Helping others calculate doses and administer medicines safely.

In 2011, changes to the Community Pharmacy Contractual Framework went

some way to implementing this policy through the introduction of the New Medicines Service, to help orientate patients with newly prescribed medicines and through targeting a proportion of MURs to specific groups of patients, including those newly discharged from hospital.[114] In 2015, further targeting was introduced, as described later.

The change of government in 2010 brought about a major re-organisation of the National Health Service and the introduction of a new healthcare commissioning landscape. The 2010 Department of Health White Paper, *Equity and Excellence: Liberating the NHS,* published within two months of the change of government, laid out plans to create GP-led commissioning groups from April 2013 and a national commissioning board.[21] There was limited focus on pharmacy within the paper, however, it predicted that performance-related payments to pharmacists would incentivise services and achieve better use of medicines by informing and involving patients.

Medicines Use reviews and the New Medicines Service

The 2005 Community Pharmacy Contractual Framework included provision for three levels of community pharmacy service: essential, advanced and enhanced. Essential services include the safe dispensing of medicines and appliances, repeat dispensing, disposal of unwanted medicines. Advanced services include the MUR and later the New Medicines Service (NMS).[110] The MUR aims to assess the patient's use of their medicines, increase their knowledge of their medicines and identify where they are experiencing problems with them. Advanced pharmacy services such as the MUR and NMS should theoretically allow them to work in a more integrated way with other members of the healthcare team to provide support to patients in the use of medicines. Enhanced services (now referred to as locally commissioned services) include full clinical medicines review, minor ailment services, supplementary prescribing and out of hours medicines access.

MURs are an opportunity for pharmacists to influence medicines safety and to work collaboratively with other members of the primary care team through improving the use and outcomes of medicines. The focus is on improving patient understanding of medicines and how they should take them and community pharmacists can use a standard feedback form to highlight with the

GP any potential drug interactions, potential side effects or adverse reactions, non-use of the medicine by the patient, difficulties using the medicine, problems with dosage, and concerns the patient has. The pharmacist can provide further information to the GP and make recommendations for possible action. Perceived by professional groups as, in principle, a facilitator of more integrated professional care, in practice the quality of the feedback provided by pharmacists has been the subject of criticism by GPs,[115] and patients do not always understand or appreciate them.[116] There is, however, evidence that MURs conducted after discharge improve the safety of patients' medicines.[117]

Three national patient target groups for MURs were introduced in October 2011: those taking high-risk medicines; those whose medicines have recently been changed whilst they have been in hospital and have recently been discharged; and those with respiratory disease. Initially 50% of MURs conducted annually by each pharmacy had to be with people in these groups. This was increased to 70% from 31st March 2015 as part of NHS England's commitment to support patients with chronic conditions. A further target group of patients at risk of cardiovascular disease who are regularly prescribed four or more medicines was also added.

The NMS commenced in October 2011 to offer support to those patients with chronic health conditions who had been prescribed a new medicine. The aim of the service was to help improve patient adherence, increase patient engagement with their condition, reduce wasted medicines, reduce adverse drug events and hospital admissions, and increase reporting of adverse drug events. It was designed to focus on four clinical areas: respiratory (asthma and chronic obstructive pulmonary disease (COPD); type 2 diabetes; antiplatelet/anticoagulant therapy; and hypertension. In common with the MUR, the NMS feedback form allows the community pharmacist to highlight concerns with a patient's new medicine, including possible drug interactions, side effects, patient non-use, patient difficulties using medicines, and patient concerns about medicines. Hospitals can refer patients to their community pharmacist for an NMS appointment to support their medicines use. The national referral form allows the hospital to list new medicines and the adherence support the patient is likely to need. The service was initially funded until March 2013 and, since then, decisions about the continuation of the service have been made annually;

although a recent evaluation indicated its success in increasing adherence by approximately 10% whilst also reducing costs.[118] Improvements suggested were further support to pharmacists to improve the patient focus of the NMS, training and peer support for pharmacists and enhanced integration of the NMS into primary care.

Recent policy has explored moving pharmacy even further towards integrated, clinical roles. In 2013, the RPS published the report of its Commission on Future Models of Care outlining its vision for the future role of pharmacy in the English NHS.[119] Despite the complicated commissioning and NHS funding landscape, it emphasised pharmacy's role in providing integrated care and how pharmacists could play a crucial role in urgent and out-of-hours care. It stressed how, as a profession, pharmacy needs to become less insular and that different contracting and delivery models may be required to provide care to meet NHS and patient needs. Amongst its recommendations was the shift in the balance of funding from pharmacy dispensing roles to medicines optimisation roles.

In the same year, the Scottish Government published their *Review of NHS Pharmaceutical Care of Patients in the Community in Scotland*.[120] It discussed how delivering effective pharmaceutical care is only possible if people and healthcare professionals view pharmacists as core primary care team members. The Scottish Government's response, entitled *Prescription for Excellence: A Vision and Action Plan for the Right Pharmaceutical Care through Integrated Partnerships and Innovation*, set out its long-term vision for the profession.[121] This included multiple delivery models complementing and supporting GP services. Radically, it undertook that by 2023 all pharmacists working in primary care in Scotland will be NHS accredited clinical pharmacist independent prescribers offering community-based clinical care. Their role would work with other HCPs to manage long-term conditions. Little is yet known about how services within primary care will be re-organised to facilitate the delivery of this vision, however very recently the Scottish Government announced it had earmarked £16.2 million over three years to employ 140 pharmacists to work with GP practices as independent prescribers.[122]

Most recently, NICE medicines optimisation guidelines identified a role for pharmacists, amongst others, in medicines reconciliation after patients have

been discharged from hospital, in undertaking medicines review and in making strategic decisions about medicines (NICE, 2015).[72] In addition, a recent report by the Health and Social Care Information Centre highlighted the success of a proof-of-concept project giving community pharmacy access to patients' summary care records (centrally held electronic records of clinical patient information including a medication, allergies and adverse reactions to medicines) and approval for implementation of community pharmacy access.[123] The proof of concept report is noticeable for its lack of a patient viewpoint, and there was some media concern about the risk of patient information being misused by businesses owning pharmacy chains.[124]

1.2.6 Community pharmacy at the transfer of care

There is some evidence that an enhanced role for UK community pharmacists in post-discharge medicines management can bring about better patient outcomes. Studies have shown community pharmacists are able to identify medicines-related problems in discharge prescriptions;[125–128] and improve the transfer from hospital to primary care through identifying and rectifying medication errors.[129] In an earlier UK controlled trial of 501 patients aged 16-69, Duggan et al. gave an intervention group a letter listing their drugs and asked them to give it to their community pharmacist when collecting their drugs.[93] The comparison group were given no letter. Patients were visited at home following receipt of their drugs. Lower rates of discrepancies were recorded for the intervention group 32% versus 53%, and those discrepancies that might have had a 'definite adverse effect' were lower in the intervention group (1.6% vs 3.1%). The chances of being exposed to an 'unintentional discrepancy' increased with the number of drugs used. The researchers concluded that providing community pharmacists with discharge summaries reduces unintentional discrepancies. In a later 2007 review conducted to assess the impact of pharmacist-led post-discharge enhanced medicines management services for heart failure patients, Ponniah et al. found evidence that medicines management programmes had contributed to better patient outcomes and that the provision of pharmacist home visits may be valuable to patients in supporting medicines optimisation.[130] Variation in study designs and patient characteristics made comparing the different effects of the studies difficult. A Netherlands study involving 37 community pharmacists compared the

experiences of patients in receipt of a community pharmacist intervention following their discharge with those in receipt of normal care.[131] The intervention comprised home medicines review and counselling at home. Those in the intervention group experienced more changes to their medicines and pharmacists took away unneeded medicines supplies. Patients in the intervention group reported higher levels of satisfaction. In summary, interventions offering home-based services may enhance patients' safe use of their medicines, however it is a resource-intensive means of offering care and more research is needed to determine its feasibility.

This section has described the system of medicines management and the risks that exist within the system, with a focus on the risks to safe medicines use when patients' care is transferred after a hospital stay. It has also outlined successive policy to re-position community pharmacy in a role supporting patients' safe and effective use of medicines, and discussed the risks.

1.3 Summary of the introduction

Evidence suggests that that there has been some success to date in programmes aimed at reducing the risks faced by patients caused by weaknesses in the overall system of medicines management. There is a global focus on patient safety and it is internationally acknowledged that patients experience risks to their safety when their care is transferred from hospital to home. UK government policy has acknowledged failings in the health system that place patients at risk and recommended that systems-based approaches are implemented to address them. Traditionally, however, systems-based approaches do not acknowledge the patient's potential to increase system resilience.

One suboptimal care system that places patients at risk is that which manages their medicines during the transfer of their care after they have left hospital. Models mapping medicines management have not viewed the system from the patients' perspectives and so fail to be patient-centred, despite current UK policy to provide patient centred-medicines optimisation services. Patients have potential to add resilience to the medicines management system through their self-management of medicines and through their interactions with healthcare professionals.

A range of policy initiatives and strategies to implement policy recommendations have attempted to enhance the role of community pharmacists in medicines management, and specifically after hospital discharge, for example through the MUR and the NMS. These services are designed to increase resilience through enhancing patients' abilities to manage their medicines and identify potential problems with medicines sets. The WHO and NICE recommendations also champion the patient's own role in the safety of medicines management when their care is transferred; however the patient's own role in the system remains ill-defined. The literature review in the next section, therefore, will focus on exploring patients' experiences of the medicines management system after discharge from hospital. Drawing on this literature, it will explain and appraise where possible the current role of patients in managing their medicines after discharge and the impact of the system on them.

Chapter 2 – Literature Review

The narrative literature review in this chapter explores the international evidence about how patients experience medicines management after their discharge from hospital. It covers the period from 1990 to July 2014. This period was selected because the landmark Harvard Medical Practice Study detailing the level of preventable harm caused to patients was first published in the early 1990s, introducing a new era in the study of patient safety in healthcare. It was decided that earlier research would arguably lack relevance to an understanding of modern healthcare systems. The review aims to determine what is already known about patients' experiences of and roles in medicines management, understand the benefits and limitations of the methods used in the research studies and draw out inconsistencies. Whilst the benefits of systematic reviews are recognised, in particular their use of explicit and unbiased processes to synthesise the literature,[132,133] a narrative approach was considered more effective at uniting the myriad study designs across a wide range of topic areas relevant to this study.[134] A systematic review would have limited the breadth of research included in the review. A narrative method allowed a deep understanding of the impact of healthcare systems on patients during this period.

2.1 Method

A flexible and iterative approach to searching the literature was adopted. Searches were made using the keywords 'hospital discharge' and 'patient discharge' combined with the terms 'medication(s)'; 'medication error', 'drug errors', 'adverse drug events', 'patient experience'; 'compliance'; 'persistence', 'continuity' and 'adherence' in MEDLINE, PsychInfo, and CINAHL. The search was limited to January 1990 to July 2014 and to English Language publications. The search strategy produced 2,456 records. Titles were reviewed and 546 abstracts were obtained for further review.

Abstracts were reviewed against the following inclusion criteria:

i) A patient voice was included in the research – studies that explored discharge medicines from the perspectives of HCPs alone were excluded, as were those that examined documentary sources only;

ii) Studies were conducted in the three months after discharge to capture the immediate post-discharge period;
iii) Studies in which patients were discharged to their own home;
iv) Studies about which the main focus was medicines, rather than hospital discharge generally;
v) Empirical research studies.

Excluded studies were:

i) Studies exploring discharge to care facilities (because patients' medicines would be the primary responsibility of staff rather than of the patient);
ii) Studies of patients leaving emergency departments;
iii) Studies reporting results of interventions as these do not report a 'normal' patient experience;
iv) Studies that solely validated scale measures;
v) Studies not in the English Language;
vi) Letters, conference abstracts/proceedings, editorials and other non-research records.

Full text papers (196) were reviewed and 65 retained. Additional studies (5) were identified through the references of the retained studies. Data extraction was conducted systematically, the following being recorded for all studies: the time period post-discharge when data were collected; the data collection method; the number of participants and health condition of the participants; the main findings relevant to the patients' experiences with their medicines; and the country in which the research was conducted. Whilst no studies were excluded because of their quality, an assessment was undertaken using a 16-item tool for studies with diverse designs.[135] The tool requires the reviewer to allocate a mark ranging from 0–3 for each item. Items include the existence of an explicit theoretical framework underpinning the research, clear statements of objectives and research questions, and justification of sampling and analysis methods. It was chosen as a suitable tool because of the heterogeneity of research designs in the literature. The results of that assessment are detailed in Appendix 1.

2.2 Findings

Seventy studies were included from 16 countries and a range of methods were employed at various times post-discharge. There were 30 studies from the USA, nine UK studies, and four each from Sweden, Israel and Canada. The other 18 were from other countries. One of the studies was conducted in six European countries. Only four studies made explicit reference to a theoretical framework underpinning the research. Most used quantitative methods: surveys and structured interviews were the main tools used (55); fewer studies used qualitative methods – 15 used semi-structured patient interviews, two used patient diaries, observations were used twice and focus groups just once. Few studies justified the timing of data collection relative to the time of discharge (10); this would have added context to the experiences researchers might have expected patients to have had, for example obtaining a repeat prescription or attending a follow-up clinic. Studies explored the experiences of the elderly (26), cardiology patients (14), those with mental health conditions (3), stroke (3) other health conditions (8) and some were not condition- or age-specific (16). Eleven studies included data from HCPs, comparing their views to those of patients, and two included the views of carers. Ten studies made explicit reference to involving patients in the research. In each of these, patients were involved in pilot testing or qualitative work to develop data collection tools. No studies made reference to patient involvement in the formulation of research questions, study design or the management of the research; however, one used data collected from patients to inform a later research phase with hospital staff. The review findings are described in seven thematic areas: receiving discharge medicines information; patient understanding of discharge medicines; managing discharge medicines; adherence, persistence and continuity of treatment; roles and experiences in medicines management; medicines problems identified in community pharmacy after discharge; and measuring adverse drug events.

2.2.1 Receiving discharge medicines information

A major theme in the literature was patients' accounts of receiving information about their medicines, their perceptions of medicines information they received, and their role in managing that information. A total of 15 studies employed a range of qualitative and quantitative methods to either measure or explore their experiences. They are presented in Table 2 on page 56.

Measures of receiving medicines information

The evidence about the recall of receiving discharge medicines information is conflicting. Measures were conducted in four studies;[136–139] one reported 40% of patients (n=341) recalled counselling for new medicines and 64% recalled counselling for existing medicines.[137] Over two fifths of patients (42%) wanted more comprehensive counselling, although their reasons were not explored. Patients reported preferring medicines counselling from doctors (85%). Another paper one year later from the same research group (possibly using the same data) also reported that 40% of patients recalled counselling.[138] Other Swiss patients recalled receiving information for 15% of long-term medicines and 19% of new medicines.[136] These patients (n=362) were significantly less likely to report receiving information in hospital if they reported having help with their medicines at home (CI 0.19-0.98; p=0.05); and significantly more likely to do so if the medicine had been introduced when the patient was in hospital (CI 1.2-2.0; p=0.001).

A further study of USA patients (n=104) found they were mostly (89%) in strong agreement that instructions were communicated in *language* they understood, 80% were in strong agreement that instructions were communicated clearly, however many fewer (40%) were in strong agreement that the information they received at discharge had been *easy* to understand, although the measure used was unvalidated so it is not completely reliable.[139] Inadequate written information was identified in a Danish study (n=200), in which 66 patients who used prescription medicines had no medicines list in their discharge letter.[140] A USA study of those taking insulin (n=47) found the majority 81% received written instructions and all patients that were new to insulin received written information.[141]

Qualitative studies of receiving discharge medicines information

A set of nine studies explored views of medicine information and education qualitatively. One study explored Dutch patients' perceived medicines information needs at discharge using a qualitative approach.[142] Semi-structured interviews with cardiology, pulmonary and internal medicine patients (n=31) identified four aspects of information considered important by patients: basic drug information (name, purpose, use); side effects; alternatives that could be used; and what to do if problems occur. Patients preferred verbal and written

information in combination. Unfortunately, the study does not attempt to draw comparisons between those who it described as receiving enhanced care and those who did not. In a Swedish study of patients following a heart attack, information was described as confusing and conflicting, for example information was difficult to understand because of the terminology used or the stressful environment it was given in, and GPs, nurses and hospital staff offered the patient differing accounts of their need for medicines.[143] Views about discharge medicines information were examined in depth in a UK study by Knight and colleagues.[144] Discharged elderly patients and carers (n=19) took part through responding to an advert and were given the option of completing an interview or keeping a medicines diary in addition to an interview. Their views of medicines information provision were found to be mixed, although most perceived the information they received to be inadequate, especially the level of explanation they received about changes to their medicines and new medicines. Patients and carers reported assuming that staff had no time to give them information. Written information was lacking for the majority and difficult to understand for those who had received a list of medicines. In another USA, information was judged lacking because it was thought not to be personalised to the patient.[145]

In a study of 40 older patients in New Zealand many could not recall receiving information in hospital about medicines changes and were reluctant to ask questions of hospital staff.[146] Lack of recall was more pronounced in those who had discontinued an antiplatelet medicine, rather than in continuers of 22 stent patients and patients described an lack of opportunity to ask questions about their medicines in hospital and a rushed discharge and receipt of conflicting information;[147,148] some did not recall receiving information and those who continued taking clopidogrel found other sources of information. An earlier study found that patients who had received information in hospital did not recall receiving medicines information 1-2 weeks after leaving hospital.[145] This qualitative study (an ethnography) explored ‘medicines education’ at discharge, combining observation with telephone and face-to-face interviews in a sample of older US patients (n=114) with heart disease. The authors reported that patients received ‘unstructured education’ during their hospital stay and structured education at discharge. Education was offered in varying depths and was not tailored to the patient. Those patients using anti-coagulants, those with

new medicines and those who asked more questions received more information. Patients experienced education about their medicines from both doctors and nurses, yet patients perceived the doctor to be responsible for giving them information, although nurses were seen as effective and acceptable in doing so. Patients reported preferring information before the day of their discharge to allow them time to understand it, and again at discharge so the information they received was relative in time to their departure from hospital. Education about medicines was valued when it was personalised and given verbally and in writing and, once back at home, patients were found to lack recall of their medicines education. This study might usefully have drawn a distinction between encounters that merely provided patients with information and those that used other methods to develop their medicines use capabilities.

Qualitative studies in part described patients' roles in using medicines information. Martens described how patients *"need to be aware that a goal of the hospital stay is to learn how to safely and correctly manage their medications"*;[145(p347)] thereby highlighting the role of self-management which is also mentioned in a study of patients taking warfarin who reported wanting enough information to enable confident self-management of their medicines after their discharge.[149] Other elderly patients wanted deeper involvement in decisions about medicines and once they were discharged, and therefore not immediately able to access healthcare professionals, they reported difficulty interpreting the information they received;[144] difficulty getting further medicines information;[150] or needing help creating a personal schedule to self-manage their medicines.[145] Heart attack patients used alternative sources of information, such as the internet;[143] and clopidogrel discontinuers struggled to relay medicines information to the primary care team after their discharge or interpreted information incorrectly.[147]

Summary

In summary there is a small evidence base and a lack of consistent evidence to show that comprehensive, clear and structured medicines information is received by patients at discharge. International policy considers providing information to be only one means of educating patients about their medicines,[151] and it is also understood that when attempting to influence health behaviours, providing information is only one of the range of methods

available.[152] There is also little evidence that patients are positioned in any other role than of passive recipients of information. There is some evidence that patients receive information that they subsequently struggle to recall and that patients fail to receive a usable list of their medicines. Studies that measure patient satisfaction with their medicines are of limited value; rather research should focus on how patients use their medicines and what types of patient education are appropriate to support the effective use of medicines. Two studies attempted to associate recall of receiving information to outcomes or contextual factors, for example discontinuation of medicines, or support with medicines. Interestingly those patients with support in the home in one study had lower recall of receiving information, which may be either explained by the patient's lack of ability to either recall or a lack of need to recall because they have help, although neither of these factors were explored. Conducting memory tests of what patients are told in hospital lacks value as an approach to understanding how patients might use information as part of a process of building their abilities to safely manage their medicine once they are home.

2.2.2 Patients' understanding of discharge medicines

Closely linked to patients' receipt of medicines information and how they managed their medicines before their hospital admission is how well they understand their discharge medicines. The methods employed were either pre-constructed measures of knowledge, or qualitative to explore understanding of medicines. Here these two different types of study are discussed separately.

Measures of knowledge

Many of the studies attempted to produce a quantitative assessment of patients' knowledge of their discharge medicines. A total of 13 studies used quantitative methods to measure patients' knowledge; summaries of those measures are presented in Table 3 on page 59. The studies ranged from 1995 through to 2011 and there is no evidence that over this period patients' knowledge of the medicines which they left hospital with improved, although the exact focus of each study differed. Areas explored were: knowledge of medicines at discharge;[153,154] after discharge;[137,155,156] the association of medicines knowledge with use of health service;[138] measured of understanding of changed or new medicines;[138,155,157,158] the association of reports of receiving information at discharge with knowledge of medicines after discharge;[136] the outcomes of

discharge preparation;[159] the differing perceptions of patients' knowledge amongst patients and doctors;[160] and the medicines knowledge of elderly patients.[161] Specific health conditions included cardiology and lung conditions;[158,160] diabetes, hypertension, cardiology and lung conditions;[138] and immunocompromised patients.[154] None of the studies used a validated measure for knowledge of medicines.

Each study measured patients' knowledge of their medicines in a different way. Purpose and name of medicines were commonly asked, along with knowledge of side effects, whilst patients were questioned less often about their doses and dose frequency. However, medicines naming is a limited means of assessing patients' knowledge of their medicines: names will change if prescribers choose to move between brands or from brand to generic and vice versa. Names are often complicated, and can sound very similar. Patients taking many medicines concurrently may also – quite justifiably – have problems remembering them all. A patient may be more likely to remember the name of a medicine that they were already taking before going into hospital and less likely to know the name of a newly prescribed medicine. Questions about the purpose of medicines may produce a more useful marker of medicines understanding, and possibly a superior indication of how well patients understand their medicines. In two studies patients were able to refer to notes, such as discharge summaries, which obviously would help with their ability to answer questions about their medicines, and is perhaps justifiable because it more closely reflects how patients may use their medicines, referring to any written information they may have about them.

Patients were questioned about all their medicines;[153,154,156,159–161]some about only long-term medicines;[136,138] and others about new and changed medicines.[155,157,158] One study questioned patients about one continuing medicine and one new medicine.[137] Variables negatively associated with medicines knowledge were reported to include age and the number of medicines taken.[136,155,156]

In adjusted logistic regression analysis, reasons for taking medicines were less likely (0.4 times – CI: 0.22-0.76) to be known by patients aged 80 or over when compared to patients aged 20–59, more likely to be known by those who had

reported receiving information during their hospital stay (7.2 times – CI: 3.2-16.1).[136] Patients in this study who stayed longer in hospital were 0.96 times as likely for each additional day to know the reasons for taking their medicines once they were discharged (CI: 0.94–0.99) and it is possible that a longer stay in hospital may have given patients the opportunity to familiarise themselves with their medicines and also to receive more information about them.

Logistic regression models were used to identify the best predictors of patients' medicines knowledge: those on only one or two medicines at discharge were 5.8 (CI: 1.7-17.02) times more likely to correctly report how to take their medicines.[156] A slightly earlier study of 119 elderly patients measured a correlation between knowledge of medicines and cognitive function, and between knowledge and the number of prescribed drugs, but did not find an association between knowledge and age, although the mean age of the sample was 82.[161]

A significant correlation ($p<0.001$) was found between recalling receiving medicines counselling and correct knowledge but not with gender, age, education, satisfaction with counselling, nor wanting more counselling in a study of 341 patients.[137] Only one study compared patients' knowledge with doctors' assessments of patients' knowledge.[160] This single-site US study compared the responses of hospital doctors and patients (66 pairs) and found that there was general agreement about patients' good understanding of their medicines, however doctors reported that 89% of patients understood the possible side effects and fewer patients (57%) reported that they understood. Doctors in this study were also found to perceive that more time was spent discussing post-discharge care than patients did.

Qualitative approaches to exploring patients' medicines understanding

Qualitative approaches have more recently been used to explore patients' understanding of their discharge medicines. Studies that in part explored medicines understanding are presented in Table 4 on page 63. One study undertaken in New Zealand explored elderly patients' experiences using their new and changed medicines after their discharge.[146] Patients (n=40) described trusting their doctors' decisions about their medicines and a reluctance and lack of opportunity to discuss changes with hospital staff. Nearly half the sample was

unaware of how their medicines had changed. The study focussed on patients taking four or more medicines, which may mean they have a more complicated medicines management role than those taking fewer medicines. Elderly patients in another study reported being confused by the set of medicines they were given at discharge and the complicated regimen they were asked to follow; and their lack of understanding affected their confidence.[144] In another study of UK patients, understanding what their post-stent medicines were for was thought to impact on their adherence although patients believed knowing what their medicines were for was important.[163]

Other aspects of knowledge explored were about specific medicines, for example USA patients discontinuing clopidogrel reported having poor knowledge of the duration of their treatment.[148] Other research also found patients to have inadequate medicines knowledge: when participants were asked about their stroke medicines, understanding varied, but no participant had complete knowledge.[164] A study conducted by Stafford et al. used qualitative semi-structured interviews to explore Australian HCPs' and patients' experiences and perspectives of warfarin management in the period after hospital discharge to identify issues in the existing medicines management systems.[149] Interviews were conducted with nine patients, along with eight GPs/practice managers, eight special support service providers, five healthcare organisation representatives, and 12 community and hospital pharmacists. Amongst the themes identified in the phenomenological analysis was that patients who were well informed appeared comfortable with their warfarin therapy; and others described being confused or anxious about warfarin, which arose from a poorer understanding of their treatment. Medicines review services delivered at home after hospital discharge allowed patients to ask more questions because they were in a comfortable environment and were perceived by some patients to enhance the system of warfarin management because of improved access to services.

Summary

Overall, there is no compelling evidence that patients understand the medicines they leave hospital with and more vulnerable patients, for example those who are older and self-managing more medicines may, quite understandably, be less knowledgeable about aspects of their medicines. The number of studies,

especially qualitative studies is small and many of the quantitative measures used, for example testing patients' memory of their medicines regimens, lacked relevancy to the way patients use medicines in real life. Moreover, there was no consistency in the range of methods employed to measure understanding or in the different lengths of time post-discharge data were collected. There is also little value in employing deterministic approaches to understanding whether more information, being younger, or being on fewer medicines impacts on a measure of understanding; instead, more focus could be placed on exploring how the model of service provision impacts on patients' self-management of their medicines and research could explore how patients could be more effectively supported in developing understanding and becoming confident self-managers of their medicines. Just one of the studies, for example, detailed how a home review of warfarin after discharge gave patients the opportunity to probe for the information they wanted and the studies detailed in this section do not take into account the roles of family and other personal contacts in helping patients develop an enhanced knowledge of their medicines.

2.2.3 Patients' experience and roles in discharge medicines management

Patients' self-management of their medicines once they have left the hospital was the focus of a range of studies. In total, 19 studies were identified exploring the experiences of different groups, including: elderly patients;[144,146,161,165,166] elderly non-English speaking background patients;[167] inner-city US patients;[157] psychiatric patients;[168] those discharged from intensive care;[150] following a stroke;[164] following a heart attack;[143] following a stent procedure;[147,148,163] after surgery;[169,170] undertaking cardiac rehabilitation;[171] taking warfarin;[149] anti-platelets;[147,148] and insulin.[141] These studies are presented in Table 5 on page 64.

Practical and emotional factors

Patient responsibilities of getting and paying for medicines after discharge were highlighted as concerns in a number of studies. Patients had problems getting to the pharmacy;[150,157] and those who had difficulty visiting the pharmacist were significantly less likely to fill prescriptions on the day of discharge.[157] Other patients reported difficulties in getting timely supplies after leaving hospital.[141,150]

Some USA patients took less than prescribed doses because of the cost.[157] More than a third of these inner city patients (35%) thought it difficult to afford medicines and patients under 55 were more likely than those over 55 to report problems paying for medicines (48% vs 19%). Nigerian psychiatric patients also reported financial difficulties (44%).[168] In a large US study of discharged patients (n=31,199), 7.2% reported having a prescription-related issue (including not collecting medicines or not knowing if they had been collected) after discharge and those with Medicaid or Medicare HMO insurance or no insurance were significantly more likely to experience problems ($p<0.0001$).[162] In this study, older patients reported fewer problems, but people prescribed six or more medicines were more likely to report problems (OR 1.39; CI 1.9-1.54).

One Swedish study explored patients' experiences of taking medicines after a heart attack.[143] Interviews with 20 patients adopted a narrative approach. Patients described feeling the burden of taking medicines, lonely, and insecure. Needing to take medicines acted as a reminder that they had suffered a heart attack. They wanted reassurance from their doctor, experiencing side effects, yet feeling protected from further ill health as a result of taking medicines, which was also reported by stroke patients (n=30), along with concerns about side effects and interactions and negative beliefs about medicines.[164] Studies of patients' post-operative experiences have provided another perspective, specifically the management of pain medicines after discharge. Negative attitudes towards medicines and adverse effects also informed the use of pain medicines after discharge post-surgery.[169,170] Influence of family and friends was important in deciding whether to use pain medicines;[170] however refusal by family to be involved in care was associated with non-compliance amongst psychiatric patients.[172] Warfarin patients reported being anxious and confused.[149]

Other patients described problems adapting their medicines routines after changes made in hospital;[146] and some developed strategies to remember to take medicines, including having a place for containers and established routines.[163–165,171] Worries about medicines led to some patients adjusting their routines.[150] Problems experienced by patients with medicines packaging were identified in studies from 1996 through to 2014.[125,150,161,164]

Support managing medicines

Other studies have in part explored the role of patients' personal contacts in managing their medicines. For example, half of US inner-city patients in one study (n=84) had help from friends and family collecting their medicines, 36% had reminders from friends or family to take medicines, 28% had help from friends and family organising medicines and 33% had help from friends and family paying for medicines. Women and patients over 55 had more help picking up their medicines.[157] Over a quarter (26%) of patients had help from friends and family understanding how to take new medicines and 21% had help from friends or family deciding what to do with pre-hospital medicines. Younger patients were significantly more likely to report getting help understanding how to take new medicines and what to do with their hospital medicines. Social support with managing medicines and the types of assistance provided was also included in a US post-discharge medicines management study of elderly patients.[165] The most common type of help was preparing medicines without being asked to do so; and the most common source of help was from a spouse. Similarly, UK stroke patients described the importance of carers, such as spouses, in managing medicines.[164]

Impact of gaps in care

Patients in different countries reported poor continuity of care and poor communication about their medicines management at transfers of care.[144,147,148,164,167] Patients described a lack of contact with a GP or community pharmacist;[164] a lack of follow-up care;[147,165] and GP contact that lacked depth.[143] Most patients in a 1990s UK study of older adults post-discharge had not been seen by their GP and had not had their medicines reviewed whilst they were present.[173] Others had not received repeat prescriptions.[174] Several other studies highlighted the poor communication that patients thought occurred between care providers, including incomplete, inconsistent and confusing information.[144,148, 149,150,165,166] There is evidence that patients perceived a lack of co-ordination between hospital and primary care staff and they experienced a burden in performing a communication bridging role between their healthcare providers.[144,150] Some UK patients were not aware of the role of community pharmacy in their medicines management.[163]

Summary

This section has explored the range of research into how patients report managing their discharge medicines. Their roles comprised acquiring medicines after discharge, and creating and adapting strategies and routines to help them take medicines, including new medicines, and receiving help from personal contacts to manage their medicines. However, some patients found it difficult to adapt their routines to changes made in hospital. Patients were aware of care continuity gaps and some report bridging those gaps. No studies, however, explored how patients manage their medicines after discharge from a systems perspective or looked at the range of people and professionals involved in the medicines management system.

2.2.4 Patient adherence, persistence and continuity of treatment

Whether or not patients actually take the medicines they have been prescribed in hospital has been the focus of research with patients throughout the period covered in this review. Twenty four studies attempted to measure patients' adherence, compliance or persistence with intended long-term medicines within three months of hospital discharge. The terms persistence and adherence have been defined as two different constructs:[175] a patient is adherent if prescribed medicine instructions are followed, whilst persistence is characterised as continuing treatment for a prescribed period. Continuity of treatment in a further seven studies is explored as the extent to which discharge medicines continue to be prescribed by the patient's GP. Continuity is considered alongside medicines discrepancies, which are defined as differences between what was prescribed at discharge and the medicines the patient actually takes. Discrepancies were measured in two studies, both using the USA medicines discrepancy tool (MDT).[58]

Adherence and persistence

In studies dating from 1992–2014 measures of adherence and persistence were taken at varying time-points from 48 hours after discharge up to the three-month post-discharge cut-off point for this review. Justification was rarely made for the timing of the patient follow-up. Rates of adherence were documented to be as high as 100% for stroke patients taking diabetic medicines;[176] and as low as 6.5% in USA medical-surgical patients.[177] In some cases sample sizes were very small, limiting predictive value;[177,178] and only seven of the studies were

conducted with patients discharged from multiple hospital sites. Reported adherence and persistence rates from each of the studies are detailed in Table 6 on page 68.

Measures of persistence

Three studies measured persistence, defined as *"continuing a therapy or class of therapy from discharge to the 3-month follow-up;*[179(p1457)] Each of these studies also explored if non-persistent patients had self-discontinued or if they had discontinued with the knowledge of an HCP.[179–181] One of the larger studies measured persistence with stroke prevention medicine after discharge amongst USA patients (n=2,598).[179] Regimen persistence comprised taking all classes of medicines and composite persistence was calculated as the percentage of medicines classes patients were still taking. The sample was 95.5% persistent with all medicines prescribed at discharge. A year earlier, persistence with evidence-based medicines for USA patients with acute coronary syndromes (n=1107) was recorded three months after discharge.[181] They found patients to be less persistent (71.8%) and in 61.5% of those cases the patient had decided to self-discontinue. Persistence was associated with fewer types of medicines classes, increasing age, medical history, less stroke disability, insurance, working status, knowledge of medicines, increased quality of life, hardship, region and hospital size.[179]

Measures of adherence

The studies identified used varying definitions of adherence and different measurement techniques or measurement scales, such as the Medication Adherence Report Scale (MARS),[182] and the Adherence to Refills and Medications Scale (ARMS).[183] Some studies measured rates of under-adherence, over-adherence and overall adherence, whilst others characterised patients as fully and partially adherent. Differences between adherent and non-adherent patients were reported as: being older (more adherent), having a greater perceived risk of not adhering, personal susceptibility to disease, satisfaction with previous treatment, cognitive memory failures, and patients' subjective value of health;[184] better self-reported health status and higher number of medicines predicted non-adherence in a study of Swedish patients;[185] adherence levels between patients on a higher number of medicines

were different in elderly Italian patients on polypharmacy;[186] whilst belief in the necessity of medicines significantly predicted adherence in a further study conducted in the Netherlands.[187] Amongst schizophrenic patients being non-compliant was associated with risk of readmission, accessing emergency care, being homeless and experiencing worsening symptoms;[172] there was also an association with family refusal to be involved in treatment and non-compliance. Compliance was associated with drug misuse and recognising symptoms. Mansur et al. (2009) found an association between non-adherence to at least one medicine and inappropriate prescription drugs prescribed at discharge,[188] although a more interesting finding in their research is that nearly half of the elderly patients (45%), were discharged with at least one inappropriate prescription medicine.

Exploring adherence qualitatively

In the UK, adherence to medicines following a stent procedure was explored qualitatively with 20 patients. They reported good relationships with GPs to be an influencing factor, along with understanding of the purpose of medicines and their health condition, having a medicines routine and perceiving positive benefits to taking medicines. Some patients were unclear about the community pharmacy role in supporting adherence, although patients were interviewed within a week of discharge so would not have had an opportunity to experience a post-discharge MUR or collect a repeat prescription.[163] A sample of Australian patients found it difficult to adhere to new medicines because the new medicines altered their routine.[167] Patient discontinuation of clopidogrel was explored in two comparative USA studies by a Kansas-based team.[147,148] They compared those patients discontinuing (stopping completely) clopidogrel with continuers;[147] and patient and clinician views on reasons for discontinuation,[148] however the clinicians interviewed were not involved in the care of the patients, which limits the value of the comparison. Both studies found that system-related factors, such as poor communication and gaps in care transitions, contributed to patients stopping taking their medicines. These studies are included in Table 5 (previously referenced on page 41).

Medicines discrepancies and continuity of treatment

A range of studies looked at discrepancies in medicines use and the continuity of patients' medicines in the period following their discharge. Studies used

primarily quantitative methods to generate evidence about the stability of patients' medicines use after leaving hospital. They are presented in Table 7 on page 73.

Discrepancies were identified in hospital medical records and patient reports of medicines for elderly US patients (n=80): congruence was found in only six of these patients and patients reported taking significantly more medicines than recorded in hospital records (p=0.001).[139] A Swedish study using structured interviews one week after discharge, again with elderly people, identified 30% of patients to be using their medicines as documented in their medical record, which included changes made by their primary care team after their hospital stay.[189] Discrepancies in medicines were also reported qualitatively by discharged patients from non-English speaking backgrounds in Australia.[167]

A Medication Discrepancy Tool (MDT) constructed for use with elderly patients attempted to assess the prevalence and predicting factors of post-discharge medicines discrepancies.[95] In this US study (n=375) based on one site with patients with different health conditions, 14.1% experienced one or more discrepancies and patients with discrepancies were on average taking significantly more medicines. Discrepancies were attributed either to the patient or to the system. Non-intentional, non-adherence was the most common discrepancy associated with the patient, whilst poor quality discharge information was the most common system discrepancy. Those patients taking more medicines (OR 1.13, CI 1.04-1.23) and those with congestive heart failure (OR 2.1, CI 1.09-4.03) were more likely to experience discrepancies. Rates of readmission within 30 days were also significantly higher for those patients with discrepancies (14.3%) than for those with no discrepancies (6.1%). Understanding the causes of discrepancies can reveal failures in the system, yet they fail to show how system-level and patient-level factors interact, for example, how poor quality discharge information or conflicting information may directly lead to non-adherence. They also fail to take into account individual variation in care interactions, for example, the nature of the network of professionals surrounding the patient. The MDT was later used in another USA study with 103 elderly patients.[39] Over half the sample (52%) had discrepancies about one week after discharge, and an association was found between cognitive impairment and higher rates of discrepancy, as well as with lower

levels of medicines knowledge. A different USA study found that 56% of patients had medicines discrepancies two days after discharge. In this study taking medicines not listed on the discharge summary and not taking listed medicines were categorised as discrepancies as well as taking medicines incorrectly. The authors assessed the most common cause to be inaccurate discharge instructions, followed by intentional non-adherence.[190] They found that those patients with inadequate or marginal health literacy were more likely to unintentionally be non-adherent.

A Danish study (n=200) also found wide-ranging incongruence between discharge medicines lists and patient medicines use a few days after discharge.[140] Reconciliation errors and poor communication were the main cause of incongruence. Continuity of treatment was explored by a number of studies throughout the 1990s through to 2012.[39,161,173,174,191–193] The largest, conducted in Australia, combined in-patient medical record review, a GP survey, and a patient telephone survey three months after discharge for 1319 patients from 49 hospitals after a heart attack.[193] It found a significant decrease in prescriptions of antiplatelets, statins and beta-blockers, and all four recommended medicines in combination (which include ACE inhibitors / (AII)-antagonists). Patients reported that GPs had stopped 44% of these medicines. The prescription of all four guideline-recommended medications was greater in male and younger patients. Little detail is offered about the structure of the questions patients were asked and whether they referred to any written information on their medicines during the survey.

Eijsbroek et al. reported on the continuity of medicines focussing on intensive care unit (ICU) admission, ICU discharge and hospital discharge for 21 patients.[150] They reported that 107 medicines were prescribed regularly before ICU admission, 150 were prescribed on ICU discharge, 121 at hospital discharge, and 108 three months later. Eight (5.3%) chronic medicines were discontinued on the ICU and not restarted on discharge (mainly diabetic medicines). The authors did not report on any documented reasons why medicines had been stopped. Other assessments of medicines continuity explored the experiences of elderly patients using structured questionnaires and home visits.[161,173,174,192] A small study (n=56) of UK elderly patients attempted to assess the extent of prescription continuity.[174] They found 63% of prescriptions

were unaltered by the GP after discharge; however this figure only includes additions and omissions and not changes in dose, direction and name. 27% of patients had not received a new supply of medicines and nearly half (48%) had old supplies of medicines at home. In the same year another small study found that amongst 50 UK patients 45 were taking different medicines 6–14 days after their discharge.[173] Changes included the name of the medicine (20 patients), new medicines (20), stopped medicines (10), changed directions (11) and altered doses (11). In the Mansur et al. study of 198 elderly patients one month after discharge, 16% had no changes to their medicines one month after discharge.[192] Patients who visited their GP only one time in the month after discharge had significantly fewer changes than those who visited more times or didn't visit at all ($p < 0.05$). Half of all changes were an addition of a medicine or an increased dose, over a quarter (26%) were discontinuing, 16% omitting it, and 8% switching it for an alternative. The majority of changes (70%) were due to recommendations by specialists or a change in the patients' health, the remainder were mostly due to adverse effects, poor adherence by the patient and administrative reasons. Patients who were non-adherent to at least one drug had significantly more changes to their medicines than those who were adherent.

A study of the effectiveness of the system of medicines management for discharged elderly patients conducted in the late 1990s (n=68) found more than half of patients experienced problems with their medicines, which were assessed to be due to actions or omissions of HCPs, such as incorrect drugs, doses and drug combinations being prescribed in primary care, and patients purchasing unsuitable over the counter medicines.[166] This study is noteworthy as it examines system-related problems in UK healthcare in advance of more well-known work applying systems thinking in the healthcare and medicines context.[63,194] That it was conducted on only one site limits generalisablity and its age restricts its relevance to current healthcare systems.

Summary

This section has described the literature about whether patients continue to take or continue to be prescribed the medicines they are prescribed at hospital discharge. It has found that rates of adherence vary greatly and studies have found association between adherence and a range of patient and care

characteristics. None of the studies explored the structure of patient care as a predictor of adherence, however two qualitative studies concluded that system-related problems contributed to sub-optimal medicines use. A range of terms are used, each describing slightly different phenomena, for example adherence, persistence and continuity. Discrepancies and changes were also explored. Studies described here tended to be deterministic, rather than interpretivist; they attempted to measure and predict causes of behaviour, rather than describe, explore and understand them. They did not focus on contextual factors, such as the structure of the care experienced by patients relating to their medicines, how they accessed healthcare providers, or the level of support they had with their medicines at home. As a result, most of the reviewed studies provide varying numeric assessments of rates of adherence, persistence and continuity without an extensive narrative that explains the reasons why patients may not take medicines as the hospital intended.

2.2.5 Medicines problems identified in community pharmacy after discharge

Patient-reported experiences were identified in two studies focussing on medicines-related problems identified in community pharmacies after hospital discharge. These studies are presented in Table 8 on page 75. They analysed the nature and frequency of post-discharge drug-related problems (DRPs) and community pharmacy intervention.[125,127] In the earlier study, 451 DRPs were identified during community pharmacists' post-discharge medicines discussions in 277 of 435 patients in six European countries (63.7%) (Austria, Denmark, Germany, the Netherlands, Portugal, and Spain).[125] The most common DRPs were patients' uncertainty about the aim or function of the medicine (29.5%) and their side effects (23.3%). Proxy interviews were conducted with those who could not be interviewed because of age or illness, which may have limited the ability of the study to record problems for those patients. Cardiovascular medicines were the ones most frequently associated with problems (30.5% of 358 medicines). The most common interventions performed by community pharmacists were medication counselling (39% of 305 interventions) and practical instruction (17.7%). A later Dutch study recorded existing or potential drug-related problems affecting 95.9% of 340 elderly patients using a checklist of common DRPs, the pharmacy computer system, record review and a semi-

structured interview.[127] Using the checklist, the most common DRP was having no medicine prescribed but there being a clear indication (16.1% of 992 DRPs), followed by an unnecessarily long duration of treatment (10.7%), and interactions identified on the pharmacy computer system (9.8%). Over a sixth (17.5%) of the DRPs were fear of side effects reported in interviews and 14.6% of DRPs were insufficient patient knowledge of the medicine. The authors reported that, using linear regression, the number of DRPs was significantly associated with the number of medicines prescribed per patient ($p<0.001$), the ward (pulmonary vs cardiology) ($p<0.05$) and the disease (diabetes) ($p<0.05$); age and gender were not significant variables in the model.

Summary

Studies indicated that community pharmacy is able to identify problems that discharged patients may experience with their medicines after they have left hospital, and that between 64–96% of discharged patients experienced a medicines-related problem after their discharge. The different methods used by each of the studies to collect data, the older age group in the later study, and the different definitions of DRPs might explain the discrepancy in the rates of DRPs experienced by patients reported in each study. For example, semi-structured interviews may elicit more information about problems than structured interviews; and 'fear of side effects' might arguably be more common than actually experiencing side effects. The studies record a higher incidence of DRPs and community pharmacy interventions than those conducted after discharge using records alone,[126,195] which may indicate that involving patients is a more successful way of identifying problems, especially those involving patients' knowledge of and attitudes towards their medicines.

2.2.6 Measures of adverse drug events

Measurements of error in healthcare and adverse events are considered problematic for several reasons, including the challenges inherent in developing robust measurement tools that are reliable, valid, sensitive and specific, and through the different ways data are collected and the variation in outcome measures.[196] Six studies used quantitative methods to measure the incidence of adverse events (AEs) or adverse drug events (ADEs) after discharge through patient self-reports;[48,166] and self-reports and medical record review / GP input.[47,50,51,197] They are summarised in Table 9 on page 76. Each used slightly

different measures or operational definitions which makes synthesising their findings and drawing conclusions about the rates of ADEs difficult. One study measured adverse outcomes from fall-risk-inducing drugs (FRIDS), number of medicines and drug-drug interactions (DDIs) for 'robust' and 'frail' elderly patients (n=204) discharged after a fall.[197] The total rate of adverse outcomes for the sample was 58% (39% of the robust sample and 76% the frail sample). Finally, a Croatian study followed up patients assessed to have potential drug-drug interactions (DDIs) after thirty days to assess if an adverse drug reaction (ADR) had occurred assessed clinically via patient self-report;[198] 190 patients from a sample of 222 had potential DDIs, whilst only 21 (9.5%) had actual DDIs. ADEs occurred in 19 patients (8.5%), with ACE inhibitors being the most common medicine in instances of ADEs. Only patients with potential DDI were followed up, which might yield a higher incidence of adverse reactions, the incidence in this study was low. The incidence of potential DDIs at discharge was, however comparatively high.

Summary

Together, these studies suggest that the incidence of ADEs up to one month after discharge is 9-58%, and there is a pattern in the studies that might suggest that the risks include being older and taking a high number of medicines. Risk factors have also been found to include patient gender (female), and poor patient/health professional communication across sectors of care were thought to contribute. There are, however, problems interpreting the findings. For example, the three Forster-led studies (the Forster et al. 2005 study was a reanalysis of the data used in their 2003 study) used patient self-reports or a combination of records and self-reports to determine incidents and their severity.[47,50,51] The earlier Gray et al. study on the other hand solely used self-reports, which may underestimate symptoms.[48] For example, patients may not wish to discuss their side effects or may not attribute how they feel to their medicines. In addition, studies using medical records to identify AEs may be subject to underreporting, as medical staff may be reluctant to document the cause of a readmission if they perceive a colleague or themselves to be at fault or they judge the events to be unlikely to cause harm. Furthermore, all patients in one study had a history of falling and may be more susceptible to further adverse events. Despite the different ages of participants, varying measures,

and that in some cases symptoms and problems were self-reported, the results still indicate a measurable incidence of problems with medicines after discharge from hospital. Interestingly, none of the studies asked patients whether they had reported the adverse drug events to a HCP, which would have given an indication of the rate at which post-discharge ADEs go unreported.

2.3 Literature review discussion

Seventy studies were identified as meeting the inclusion and exclusion criteria. Mapping each study against the quality assessment tool indicated that most were of limited quality. Whilst studies explored many areas of patients' experiences with medicines after leaving hospital, there was a lack of consistent evidence that patients are effectively prepared to be confident and competent medicines self-managers after they leave hospital. In particular, there is little evidence that comprehensive, personalised preparation is given to patients in a way that is usable for them once they have been discharged and studies focussed on 'information' provision rather than exploring other ways of preparing patients to use their medicines. More vulnerable patients and those whose medicines have changed in hospital may have lower levels of medicines understanding, although there is little consistency in the way medicines knowledge is measured in the included studies. After discharge, some patients played a role in developing medicines routines and strategies to manage medicines, whilst others struggled to adapt to changes made in hospital. Patients reported poor continuity of care between secondary and primary providers, and sometimes they themselves bridged gaps in care, and studies recorded a lack of continuity in treatment regimen after discharge. Post-discharge adherence and persistence rates were wide-ranging. Studies found an adverse drug event incidence of between 9–58% but there is little evidence in those studies that ADEs were due to changes made in hospital. There is also very little research focussing on the impact of people who support patients in managing their medicines.

International differences in the provision of healthcare make it difficult to draw generalised conclusions or to understand transferability and relevance of findings of the included studies. Patients in the US, for example, may not receive a supply of medicines from the hospital at discharge as UK patients do; rather they may be expected to take a prescription to a pharmacy and patients

without comprehensive insurance may struggle to finance their medicines. Despite this, it was possible to synthesize studies into themes that give an indication of the types of experience patients have when managing medicines after hospital discharge. Many chose to look at one aspect of medicines management, such as patient medicines knowledge, information provision, or adherence to treatment. It was also possible to identify major methodological weaknesses that studies held in common. Very few studies used robust sampling methods or validated quantitative measures. Within the identified research, theoretical frameworks have rarely been used to guide the development of the research and none used a human factors framework. Given the evident risks to patient safety at discharge, future research might consider adopting a systems-based framework to explore patient experiences of this critical period of care. Positioning the patient as integral to the system, capable of playing an important role within it, rather than as a passive recipient of care, may enhance the impact of research in this area to effect safer patient outcomes. Also noticeable is the very limited focus on the involvement and importance of patients' own friends and family in the safe management of medicines.

Implications for patients

International policy and UK national practice view transfers of care as a priority for improvement because of the threats posed to patient safety in current practice.[91,199,200] On discharge from hospital, patients are likely to have new medicines and/or changes to doses of existing medicines and, for a range of reasons including poor communication about medicines, they may discontinue or become non-adherent to some or all which can lead to sub-optimal outcomes including readmission to hospital.[49,101,102] Yet studies in this review found little evidence that hospitals and primary care practice effective patient preparation to self-manage medicines. The studies indicate that patients' experiences of receiving written and verbal information about their medicines are variable and sometimes inadequate, and there is no evidence of improved experience in more recent research. What unites patients in these studies is that on leaving hospital they transfer from an environment where their care is monitored to one where they may be isolated, have limited access to HCPs and have limited power and control in the management of their own care.[58] Patient care is

handed over and there is evidence that systems in primary care are not well-calibrated to receive and continue care seamlessly.

The research reviewed here has described patients' experiences of medicines discrepancies and other problems post-discharge as well as of adverse events. Patients' reports suggest they perceive that communication between HCPs in hospitals and primary care is not always effective and there is some evidence that patients' own knowledge and resourcefulness are under-used within the system; however the evidence base is not robust enough to illuminate this. This indicates that a systems-based approach to exploring discharge medicines management would be a valuable addition to the evidence base. Additionally, an approach that includes the patient as an integral part of the system and also explores in more detail the role of patients, all the HCPs who they perceive as managing their medicines, and the patients' own friends and family who support them would offer novel insight into the risks that patients face when the leave hospital with medicines, their roles in medicines management and how effectively the system functions to support them. The next section will therefore describe the methodological approach adopted to conduct that research.

Table 2: Studies of the provision and recall of discharge medicines information

Study	N=	Average age (SD)	Condition / Focus	Data collection	Time / discharge	Outcome measures / objectives	Findings
Attebring et al. 2005 Sweden [143]	20		Acute myocardial infarction	Semi-structured interview	7.5 weeks	Explore secondary prevention experiences.	Patients reported getting conflicting information from doctors and nurses which confused them and again by the primary care team. They found information difficult to understand because of the terminology and the stressful situation and physical surroundings.
Bagge et al. 2014 New Zealand [146]	40	Male median 82; female 86	Elderly with changed medicines	Semi-structured interviews		Understanding and management of changes .	Patients were reluctant to ask questions of hospital staff. Some patients reported having the opportunity to ask questions and some did not.
Borgsteede et al. 2011 Netherlands [142]	31		Cardiology, pulmonary, internal medicine	Semi-structured interviews	At discharge	Explore patients' medication information needs.	4 aspects of information considered important by patients: basic drug information (name, purpose, use); side effects; alternatives; what to do if problems occur. Prefer a combination of verbal and written instructions.
Decker et al. 2008 USA [147]	22	41-77 (range)	Clopidogrel continuers and discontinuers	Semi-structured interviews	1 month	Explore clopidogrel-taking behaviours.	Discontinuers often struggled relaying treatment information to their primary care team. Discontinuers interpreted information incorrectly or did not remember receiving information. Discontinuers reported limited time to get information from staff in hospital.
Eijsbroek et al. 2013 UK [150]	21 patients / 13 carers		ICU patients	Medication history data; Semi-structured interviews	3 months	Explore medicine-related problems arising from ICU admission and post-discharge.	Patients described a lack of explanation of interaction, and their poor interpretation of adverse effects, and conflicting information from different sources. They talked about a lack of opportunity for discussion about medicines and medicines review.
Enguidanos and Brumley (2008) USA [139]	104	76.3 (7.3)	Elderly	Survey (telephone plus physician survey and chart review)	Within three days	Satisfaction with discharge instructions.	89% strongly agreed that instructions were communicated in language they understood. 80% strongly agreed that instructions were clearly communicated.. 40% strongly agreed that the information they received at discharge had been easy to understand.
Garavalia et al.	22 (11	53	Stent patients	Semi	1 month	Congruence between	Discontinuers explained a lack of

Study	N=	Average age (SD)	Condition / Focus	Data collection	Time / discharge	Outcome measures / objectives	Findings
2011 USA [148]	continuers and 11 discontinuers			structured interviews (patients and clinicians)		patient and clinician views of reasons for discontinuing.	awareness that they should still be taking clopidogrel. Lack of opportunity to seek information in hospital. Lack of recall of receiving information. Rushed discharge.
Glintborg et al. 2007 Denmark [140]	200		Non-specific	Structured interview and record review	Within 1 week	Communication with primary care	66 patients using prescription medicines did not have a list of medicines in their discharge letter.
Kerzman et al. 2005 Israel[137]	341	66 (13)	Non-specific	Telephone interview	1 -2 weeks	Sore range 0-4 for each medicine; impact of counselling on correct knowledge.	36% of the respondents reported receiving no counselling for previous medicines; 60% reported not receiving counselling for new medicines. 88% of counselling for previous medicines was given by doctors. Counselling for new medicines was given by doctors (45%) and nurses (40%). 42% of patients wanted more comprehensive counselling about. 85% preferred to be counselled by a doctor. 59% percent preferred counselling in hospital rather than at a community clinic. 18% had counselling with their family for previous medicines and 13% for new medicines.
Kimmel et al. 2010 USA [141]	47 (11 new to insulin)	45-84 (range)	Insulin users	Structured interviews	1 week	Receipt of appropriate pre-discharge training.	81% received written instructions (100% of those new to insulin); 51% received administration instructions (100% of those new to insulin) 45% receive self-monitoring instructions (91% of those new to insulin). 96% had an insulin plan at discharge (100% of those new to insulin). Patients received instruction on insulin dosing and when and who to call for problems and questions.
Knight et al. 2013 UK [144]	19 (7 patient; 12 carers)	84	Elderly	Diary and semi-structured interview			Most reported difficulties with information: either little or no information or an assumption that staff had no time to give information. Some generated their own lists.
Martens 1998	114	76	Elderly with heart	Observation,	1-2 weeks	Describe the process	Patient education is structured at

Study	N=	Average age (SD)	Condition / Focus	Data collection	Time / discharge	Outcome measures / objectives	Findings
USA [145]			disease	telephone and face-to-face interviews		and experience of medication discharge education.	discharge and unstructured during hospital stay. Patients forget being taught about their medicines. Patients experiences education from both doctors and nurses and perceived the doctor to be responsible for giving them information, although nurses were seen as effective and acceptable. Patients needed help creating a personal schedule from a list of medicines. Only 10.5% (12) were discharged with a schedule.
Micheli et al. 2007 Switzerland[136]	362	68 (median)	Non-specific	Telephone interview	2-16 days	Association of receipt of recall of information about medicines with knowledge about long-term medicines.	Reported getting in formation for only 15% of medicines (259/1693); 19% of new medicines and 13% of previous medicines. New medicines were associated with reported of getting information. Patients who had help with medicines at home reported getting information less frequently. Patients who reported getting information in hospital were more likely (7.2 times (CI 3.2-16.1 p<0.001)) to have correct knowledge.
Stafford et al. 2012 Australia [149]	9 patients (38 professionals)		Warfarin users	Semi-structured telephone interviews		Experiences of post-discharge warfarin management.	Patients want adequate information about warfarin to be confident managing it. Well-informed patients seemed comfortable with warfarin treatment.
Toren et al. 2006 Israel[138]	130	65 (12.9)	Diabetes, hypertension, heart and lung condition; on new prescriptions for chronic diseases	Telephone interview	1 week and 1 month	Knowledge of new long-term medicines and association of knowledge with use of health services.	40% of patients reported receiving counselling about medicines.

Table 3: Measures of patients' understanding of their discharge medicines

Study	N=	Average age (SD)	Condition	Data collection	Components of knowledge	Time / discharge	Outcome measures / objectives	Findings
Brown et al. 1995 USA[159]	140	73 (6.9)	Elderly	Telephone interview	Scores 6-18/ Unclear/	Several days	Outcomes of discharge preparation. High and low medicines knowledge.	Age (older p<0.01), gender (male p<.0.05), and additional health condition diagnosis (p<0.01) predicted lower knowledge scores. Low scorers were older, less mobile, had more health conditions, less satisfied with discharge medicines preparation, less satisfied with discharge preparation, had less knowledge of activity regimen change (p<0.01 – p<0.05).
Calkins et al. 1997 USA[160]	83 patient /doctor pairs; 66 pairs for components of medicines	65.3 (15.1)	Myocardial infarction or pneumonia	Telephone interview	Purpose; side effects	2 weeks and 2 months	Agreement of patients and physicians	All patients reported understanding medicines purpose; 3 doctors did not; fewer patients than doctors (57.4% vs 88.9% p<0.001) reported patient understanding of side effects.
Chau et al. 2011 France[154]	55	41	Immunoco-mpromised	Self-administered survey	Name, dose, purpose, administration.	At discharge	Evaluate medicines knowledge and explore relationship between knowledge and patient characteristics.	57% of medicines adequately known. Knowledge of administration guidelines was worse (62% of medicines; dose most often known 83-97%. Adjuvant medicines (purposes other than chronic condition) less known than chronic medicines (except for those for infections) (OR 0.3; CI0.1-0.7; p<0.01). Being older (OR 0.6; CI 0.4-0.8; p<0.001), less educated (OR 0.2; CI 0-0.8; p=0.03), and shorter disease length (OR 1.7; CI 1.1-2.6; p=0.03), and the medicine being new or changed (OR0.2; CI 0.1-0.9; p=0.03) predicted lower knowledge.
Kerzman et al. 2005 Israel[137]	341	66 (13)	Non-specific	Telephone interview	Purpose; schedule; dose; side effects; tests needed; lifestyle requirements.	1 -2 weeks	Sore range 0-4 for each medicine; impact of counselling on correct	92% reported knowing the reason for taking their previous medication; 83% gave the correct reasons. 73% know why they are taking new medicines and 80% of those knew the correct reason.16% reported

Study	N=	Average age (SD)	Condition	Data collection	Components of knowledge	Time / discharge	Outcome measures / objectives	Findings
					One previous and one new medicine.		knowledge.	knowing about side effects of previous medicines and 59% of those patients reported correctly. 12% reported knowing about side effects of new medicines and 68% of those reported correctly. 60% of patients did not know the correct medicines schedule relative to meals. 32% had no correct knowledge of any areas of their new medicines compared to 18% with no knowledge of previous medicines. Correct knowledge and counselling are significantly correlated (p<0.001).
Kripalani et al. 2008 USA [157]	84	54.4 (11.1)	Inner-city	Telephone interview	Differences between previous and new medicines; purpose; how to take.	2 weeks	Frequency	16% struggled to understand differences between previous and new medicines; 21% thought it difficult to understand why they had been prescribed new medicines; 11% did not know how to take them. Those younger than 55 had more difficulty understanding how to take new medicines (18% vs 3%; p=0.03); those with impaired cognition had more difficulty understanding how to take new medicines (19% vs 3%; p= 0.02)
King et al. 1998 USA[156]	133	50.8 (19.8)		Telephone interview	Name; purpose; how to take; effects including side effects; things to avoid lifestyle changes.	2-6 weeks after discharge	Relationship between patient characteristics – age, number of medicines, counselling and condition – and knowledge of medicines	Number of medicines (fewer) was a good predictor of knowledge of how to take medicines (OR 5.38,CI 1.70-17.02); of names of medicines (OR 3.61, CI1.7-7.66) and what to expect (OR 4.88, CI 2.03-11.64); age (groups younger than 75) was a predictor of knowledge of the purpose of medicines.
Makaryus and Friedman, 2005 USA[153]	43	13 younger than 50; 18 50-65; 12 66 and over	Non-specific	Face-to-face interview	Name; purpose; side effects. Patients could use notes.	At discharge	Proportion able to correctly answer.	27.9% (12) patients could list all their discharge medications; 37.2% (16) knew the purpose of their medications; 14% (6) could describe the side effects of all their medications.

Study	N=	Average age (SD)	Condition	Data collection	Components of knowledge	Time / discharge	Outcome measures / objectives	Findings
Maniaci et al. 2008 USA[28]	100	63.1 (SD 16.5)	Non-specific. New medicines focus	Telephone interview	Name; number of new medicines; dose; frequency; purpose; side effects. New medicines.	3-18 days	Proportion answering correctly.	86% were aware they had been prescribed new medication at discharge. 74% knew the number of new medications and 64% could name them. 56% knew dosages and 64% knew the purpose of the medication. 22% could name an adverse effect. 11% thought they had been told about adverse effects at the time of discharge. Older people answered fewer questions about their medicines correctly.
Micheli et al. 2007 Switzerland[136]	362			Telephone interview	Name, dose, frequency, purpose.	2-16 days	Association of receipt of recall of information about medicines with knowledge about long-term medicines.	Reasons for taking medicines significantly less likely to be known for new medicines, among older patients and those staying longer in hospital. Those who received information during the hospital stay were more likely (7.2 times (CI 3.2-16.1 p<0.001)) to have correct knowledge.
Nikolaus et al. 1996 Germany[161]	119	81.9 (6.3)	Elderly	Face-to-face interview	Name; purpose.	3 months	Factors impacting on adherence.	65 patients knew the name and indication of their medicines. Knowledge correlated with cognitive function and number of medicines.19 (28.4%) reported that an unclear medicines regimen was a reason for non-compliance.
Sexton and Brown, 1999 UK[166]	29 (subsample)	80.9	Elderly	Face-to-face interview and record review	Name; purpose; colour; dose.	2 weeks	Proportion answering correctly.	20 patients (69%) could describe all their medicines (purpose/colour and dose). With prompting 14 (48%) recalled name and dose.
Toren et al. 2006 Israel[138]	130	65 (12.9)	Diabetes, hypertension, heart and lung condition; on new	Telephone interview	Purpose; schedule; side effects; lifestyle changes.	1 week and 1 month	Knowledge of new long-term medicines and association of knowledge with use of health	7% knew the reason for taking their medicines. Fewer knew about side effects (11%) and lifestyle changes (8%). 46% visited a health services within a month. Patients who had used a health service reported higher

Study	N=	Average age (SD)	Condition	Data collection	Components of knowledge	Time / discharge	Outcome measures / objectives	Findings
			prescriptions for chronic diseases				services.	medicines knowledge. Those with no knowledge visited health services less. Knowledge was a predictor of high levels of visits to health services (OR 4.76; CI1.74-13.06;)
Ziaeian et al. 2012 USA[158]	377	77.1 (7.8)	Heart failure, ACS, pneumonia. Changed medicines focus.	Telephone interview	New medicines: name and frequency. Redosed medicines: name and dose or frequency change. Stopped medicines: name. Patient could use notes.	1 week	Patient understanding classified as full, partial or absent.	Patients fully understood 33/205 (16.1%) of redosed medicines and 35/223 (17.5%) of stopped medicines. No understanding of 493 (62%) of new medicines. Most patients (79.1%) had no understanding of at least one change or all changes (63.1%). Patients were most likely to misunderstand changes to medicines deemed non-relevant to their condition (OR 2.45 CI 1.68-3.55; p<0.001)

Table 4: Studies that explored patients' knowledge of their medicines qualitatively

Study	N=	Average age (SD)	Condition / Focus	Data collection	Time / discharge	Outcome measures / objectives	Findings
Bagge et al. 2014 New Zealand [146]	40	Male median 82; female 86	Elderly with changed medicines	Semi-structured interviews		Understanding and management of changes .	Patients were unaware of and confused by changes made to their medicines and some said they would not know what questions to ask
Eijsbroek et al. 2013 UK [150]	21 patients / 13 carers		ICU patients	Medication history data; Semi-structured interviews	3 months	Explore medicine-related problems arising from ICU admission and post-discharge.	Patients were confused about whether hospital medicines were still required.
Garavalia et al. 2011 USA[148]		22 (11 continuers and 11 discontinuers	Stent patients	Semi-structured interviews (patients and clinicians)	1 month	Congruence between patient and clinician views of reasons for discontinuing.	Discontinuers explained a lack of awareness that they should still be taking clopidogrel.
Knight et al. 2013 UK [144]	19 (7 patient; 12 carers)	84	Elderly	Diaries and semi-structured interviews			Some medicines not taken because the patient didn't know the purpose.
Rushworth et al. 2012 UK [163]	20	60.5 (median)	PCI (stent)	Adherence score and semi-structured interview	7 days	Explore adherence to medicines.	Understanding what the medicines were for was thought to impact on adherence and some patients reported not knowing what their medicines were for.
Stafford et al. 2012 Australia [149]	9 patients (38 professionals)		Warfarin users	Semi-structured telephone interviews		Experiences of post-discharge warfarin management.	Patients want adequate information about warfarin to be confident managing it. Well-informed patients seemed comfortable with warfarin treatment. Patients were anxious and confused about their warfarin. Some did not receive sufficient information in hospital. They felt ill-informed about INR testing frequency and why they were taking warfarin.
Souter et al. 2014 UK, [164]	30	69 (14)	Stroke	semi-structured interview		Explore beliefs, concerns and barriers to adherence.	No-one had 'complete' knowledge and patients reported having a current lack of information.

Table 5: Studies detailing patients' experiences and roles in medicines management

Study	N=	Average age (SD)	Condition / Focus	Data collection	Time / discharge	Outcome measures / objectives	Findings
Adeponle et al. 2009 Nigeria [168]	81		Psychiatric		3 months	Reasons for follow-up default and non-compliance.	77.7% felt well; 44.4% financial; 37.7% side effects; 25.9% distance; 22.2% feeling embarrassed about illness.
Attebring et al. 2005 Sweden [143]	20		Acute myocardial infarction	Semi-structured interview	7.5 weeks	Explore secondary prevention experiences .	Felt that medicines intruded on their lives and having to take them reminded them they were 'heart attack victims'. However, medicines also offered security from future ill health and they got conflicting information from HCP which affected their confidence; terminology was also stressful. They sought information on the internet and from pharmacy. Contact with HCPs lacked depth. After discharge they were lonely and insecure.
Blennerhassett and Hilbers, 2011 Australia [167]	18		Non-English speaking	Semi-structured interviews with patients. Focus groups with clinicians	2 weeks	Explore medicines management after discharge .	Discrepancies between discharge summaries, GP records and hospital records. Interpreters not used in hospital. Received help from family members packaging or labels in their own language helped them. Education about changes and dose administration aids.
Bremner et al. 2010 Canada [170]	14		Knee surgery	Semi-structured interview	3-9 weeks	Investigate analgesic use.	Advice of family and HCPs and physical and cognitive influenced use of pain medicines. Patients limited and reduces the medicines their used.
Burns et al. 1992 UK [174]	56	82	Elderly	Home visit and medicine therapy assessment	5 days	Explore post-hospital discrepancies.	15 had not received a repeat prescription. Four patients had been visited at home by their GP. 48% had old medicines at home. In total GPs had added 14 new medicines17 had been omitted.
	179	75 (6.96)	Elderly	Structured		Explore medicines	53% had communicated with a doctor

Study	N=	Average age (SD)	Condition / Focus	Data collection	Time / discharge	Outcome measures / objectives	Findings
Conn et al. 1992 USA [165]				interview		management after recent discharge.	since discharge and 36% had been visited by a nurse. 94% reported different strategies to remember to take medicines (11 strategies). 51% reported no-one helped them with their medicines. Types of help were preparing medicines, reminders, administering medicines and checking for accuracy.
Decker et al. 2008 USA [147]	2008	22	Clopidogrel continuers and discontinuers	Semi-structured interviews	1 month	Explore and compares clopidogrel-taking behaviour.	Lack of continuity between in-patient and outpatient care. Described a lack of follow-up care. Perceived conflicting information. Extensive gap were not reported in continuers of clopidogrel.
Eijsbroek et al. 2013 UK [150]	21 patients / 13 carers		ICU patients	Medication history data; Semi-structured interviews	3 months	Explore medicine-related problems arising from ICU admission and post-discharge.	Worries about medicines led patients to adjust routines and to poor adherence. Patients had problems getting supplies and opening packaging.
Garavalia et al. 2011 [148]		22 (11 continuers and 11 discontinuers	Stent patients	Semi structured interviews (patients and clinicians)	1 month	Congruence between patient and clinician views of reasons for discontinuing.	Patients reported poor communication at care transfer.
Kimmel et al. 2010 USA, [141]	47 (11 new to insulin)	45-84 (range)	Insulin users	Structured interviews	1 week	Receipt of appropriate pre-discharge training.	10 patients had difficulties getting supplies.
Knight et al. 2013 UK [144]	19 (7 patient; 12 carers)	84	Elderly	Diaries and semi-structured interviews			Some patients created their own medicines charts. Participants felt the burden of responsibility of making sure primary care records and CP records were updated.
Kripalani et al. 2008 USA [157]	84	54.5 (11.1)	Inner-city	Telephone questionnaire	2 weeks	Use of prescription medicines after hospital discharge.	22% had not filled their discharge prescriptions two days after their discharge. Costs, transport and waiting times at the pharmacy were given as barriers. 35% said it was difficult to pay for medicines. 38% had difficulties getting to the pharmacy. 16% struggled

Study	N=	Average age (SD)	Condition / Focus	Data collection	Time / discharge	Outcome measures / objectives	Findings
							to understand differences in previous and new medicines; 21% thought it was difficult to understand why they had been prescribed new medicines; 11% did not how to take them. Those younger than 55 reported more difficulties paying for medicines (48%v19% p=.007) and more difficulty understanding how to take new medicines (18%v3%; p=0.03). Those with impaired cognition had more difficulty understanding how to take new medicines (19%v3% p=0.02).
Kripalani et al. 2008b USA [162]	31199	61.1 (17.8)	31199	Telephone interview	48-72 hours	Rates of prescription-related issues.	7.2% had an issue: not obtaining medicines (79.8%); not knowing if they had been collected (2.4%); not taking (6.8%); not understanding how to take (11%).Being younger (p<0.0001); with on medicaid, medicare or no insurance (p,0.001); more severe illness (p=0.008); more medicines (p<0.0001) predicated problems. Those on inhalers had more problems.
Leegaard and Fagermoen, 2008 Norway [169]	11 (109 diaries)	55.7	Women after cardiac surgery	Paid diary and semi-structured interviews		Experiences and management of pain	Women tried to take as few pain medicines as possible.
Nikolaus et al. 1996 Germany [161]	119	81.9 (6.3)	Elderly	Home visit, chart review, interview	3 days; 3 months	Measure problems with containers and identify factor influencing poor adherence	90% could open a blister pack; 83% a 7-day compartment organiser; only 56% could open a flip-top bottle and 36.1% a child-proof bottle. There was an increase in prescription items after discharge.
Rushworth et al. 2012 UK [163]	20	60.5 (median)	PCI (stent)	Adherence score and semi-structured interview	7 days	Explore adherence to medicines	Understanding what the medicines were for was thought to impact on adherence and some patients reported not knowing what their medicines were for. Patients did not know what the role of the pharmacist was and did not want to undermine the prescriber. Patients had a system or a routine for taking medicines. And a fear of recurring symptoms which motivated them to take medicines.

Study	N=	Average age (SD)	Condition / Focus	Data collection	Time / discharge	Outcome measures / objectives	Findings
Sexton and Brown, 1999 UK [166]	68	80.9	Elderly	Patient visit, record review	13.6 days	Explore medicines management at discharge .	Poor communication between hospital and GP. 50% had seen a doctor since discharge. Nearly all had obtained further supplies. Some had problems opening packaging.
Stafford et al. 2012 Australia [149]	9 patients (38 professionals)		Warfarin users	Semi-structured telephone interviews		Experiences of post-discharge warfarin management.	Patients were anxious and confused about their warfarin. Anxious about taking warfarin because of friends and family labelling it 'rat poison'. Patients valued home delivered care.
Souter et al. 2014 UK, [164]	30	69 (14)	Stroke	Semi-structured interview		Explore beliefs, concerns and barriers to .adherence	Patients described the importance of carers (e.g. spouses) in medicines taking and having personal routines. Some had problems with packaging. Most thought medicines were necessary and protected them against further illness but were concerned about side effects and interactions. The physical and cognitive effects of a stroke meant some found it difficult to take medicines.Some patients reported a lack of GP and CP after discharge and some expressed dissatisfaction with the healthcare system.
White et al. 2010 UK [171]	15	42-72 (range)	Cardiac rehabilitation	Semi-structured interview	3 months	Patient perspectives on lifestyle modification and medicines information.	Some concern about taking medicines but patients were prepared to take them and had strategies to remember. They tolerated or sought advice about side effects. Some felt medicines helped their recovery and reduced risk.

Table 6: Rates of post-discharge medicines adherence and persistence

Author / year	Method	Condition	Patient n=	Time since discharge	Outcome measures / objective	Measures of adherence	Rate
Adeponle et al. 2008 Nigeria[168]	Survey	Psychiatric	81	3 months	Prevalence and pattern on follow-up default and non-compliance; reasons for non-compliance.	Stopping medication or altering doses by themselves.	48.5% fully medication compliant, 17.6% partially compliant and 33.8% had stopped taking their medicines.
Ahmad et al. 2012 Netherlands[187]	Telephone interview	Elderly – polypharmacy only	245		Self-reported adherence.	MARS.	Mean 23.83 on MARS scale (5-25). 51.8% reported adherence (25)
Ali, et al. 2009 USA[180]	Survey	ACS	1054	3 months	Persistence with EBCMs, reasons for non-use.	Persistent if still taking EBCMs at three months.	71.2% persistent. 16.9% through self-discontinuation.
Arnetz et al. 2010 USA[201]	Survey	Cardiovascular	449	8 weeks	Association between patient involvement during hospitalisation and outcomes, including compliance.	Compliant with taking medicines recorded at discharge.	79% compliant.
Beers et al. 1992 USA[202]	Telephone interview and chart review	Elderly	44	3 days	Evaluate non-compliance.	Non-compliance – not taking a medicine; taking less than ordered, taking more than ordered; taking a medicine not ordered.	Did not take 32% of medicines ordered, patients took an additional 61 medicines. 64% of patients used at least one medicines not ordered at discharge. 50% failed to take at least one medicine.
Bushnell et al. 2010 USA[179]	Structured interview	Stroke	2598	3 months	To measure use of stroke prevention medicines after hospital discharge.	Defined 'persistence' as those taking prescribed medicines at 3 months. Regimen persistence = those taking all classes of medicines; Composite	95.5% persistent with all medicines prescribed at discharge.

Author / year	Method	Condition	Patient n=	Time since discharge	Outcome measures / objective	Measures of adherence	Rate
						persistence = percentage of medicines classes subjects were still taking.	
Conn et al. 1991 USA[203]	Face-to-face interviews and pill counts	Elderly	178	10-20 days	Association of adherence with medicines complexity.	Mean adherence calculated though number of doses and adherence for each medicine.	Mean adherence = 0.92.Complexity not significantly association with adherence.
Ehrenreich et al. 2012 USA[204]	Interviews at baseline and follow-up	Inpatients prescribed psychiatric medicines	21	8 weeks	Adherence to psychiatric medicines and continuance with psychiatric aftercare.	% reporting taking psychiatric medicines prescribed and of those the % reporting taking psychiatric medicines every time as prescribed	85.7% taking prescribed medicines and of those 88.9% reported taking them every time as prescribed.
Gray et al. 2001 USA[205]	Face-to-face interview and pill count		147	2 weeks	Prevalence of under-and over- adherence 2 weeks after hospital.	At least one medicine with less than 70% adherence (under-adherence); at least one medicine with more than 120% adherence (Overadherence)	30.6% (45) underadherent to at least one medication; 18.4% (27) overadherent to at least one medicine.
Johnson et al. 2009 New Zealand[176]	GP and patient survey	Stroke	48	6 weeks and 6 months	Self-reported adherence; GP record and medication changes.	Discrepancies between patient report; GP record and discharge.	95% adherent to aspirin at 6 weeks; 92% with dipyridamole; 88% with Warfarin; anti-hypertension 87%; statins 88%. Diabetic medicines 100%. At 6 months: 91% adherent to aspirin; 100% with dipyridamole; 100% with Warfarin; anti-hypertention 91%; statins 91%. Diabetic medicines 100%.
Kripalani et al. 2008a USA[157]	Survey	ACS	84	2 weeks	ARMS (Adherence to Refills and Medications Scale).	Scores 10-30 on 10 questions with three answer options.	52% high adherence (scores of 10); 48% some degree of non-adherence.

Author / year	Method	Condition	Patient n=	Time since discharge	Outcome measures / objective	Measures of adherence	Rate
Krishnan et al. 2004[206]	Survey		60 (52)	2 weeks	Self-reported use of corticosteroid; pill counts and canister weights; electronic monitoring of inhalers.	Use less than 50%.	49% poor adherence ICS; 27.1 poor adherence OCS.
Lindquist et al. 2011 USA[190]	Survey at hospital discharge, record review and post-discharge interview	Elderly	254	48 hours	Explore association between health literacy and post-discharge discrepancies.	Coded responses into intentional and unintentional non-adherence and inaccurate instructions.	22.4% international non-adherence; 21.9% unintentional non-adherence.
Mansur et al. 2008 Israel[192]	Telephone interview	Elderly	198 (145 researched for adherence	1 month	The extent and reasons for modifications.	Overall adherence – the proportion of medicines taken correctly as prescribed and averaging the proportion of medicines taken by each patient. Mean adherence calculated by averaging adherence for all patients. Also calculated non adherence to at least one medicine. Non-adherence defined as 70% or less and over adherence 110% or more to all medicines.	Overall mean adherence of 96.7%. Non adherence to all medicines identified in 6% of patients. Non-adherence to at least one medicine in 30%. 27% under-adherent; 6% over-adherent.
Mansur et al. 2009 Israel[188]	Structured interview and record review		186	1 month	Explore prevalence and characteristic of patients discharged with an inappropriate prescription drug and association with continuity, adherence and readmission.	Non-adherence defined as 70% or less and over adherence 110% or more to all medicines.	29.2% non-adherent to at least one medicine. 23.3% underadherent; 3% over-adherent.
Melloni et al. 2009 USA[181]	Telephone interview	ACS	1107	3 months	Patient reported persistence with EBM and factors associate with self-discontinuation.	Persistent if still taking al EMB classes; discontinued with provider knowledge; EBM self-discontinued.	71.8% persistent; 38.5% stopped with provider knowledge / input.

Author / year	Method	Condition	Patient n=	Time since discharge	Outcome measures / objective	Measures of adherence	Rate
Mulhem et al. 2013 USA[177]	Patient interviews	Medical / surgical	46	24-48 hours	Document the level of adherence.	Comparing patient report with discharge list. Six categories of medicines errors – addition and omission or prescription medicines, addition and omission of OTC, errors in frequency, errors in dose.	6.5% complete adherence, 78.2 reported taking one additional prescription medicine, 43.4% missed one medicine, 43.4% wrong dose of at least one medicine, 41.3% taking at the wrong frequency.
Nikolaus et al. 1996 Germany[161]	Home interview	Elderly	119	3 days and 3 months	Impact of problems on compliance.	Non-adherence to directions on container label.	43.7% taking medicines in accordance with prescriptions; 31.9% taking reduced dose; 11.8% taking higher dose; 12.6% not taking at all.
Olfson et al. 2000 USA[172]	Structured interview before discharge and at follow up	Schizophrenia	213	3 months	Identify factors predicting non-compliance	Those who acknowledged stopping their medicines for one week or more were judged non-compliant.	19.2% non-compliant; 80.8% compliant.
Pasina et al. 2014 Italy[186]	Structured phone interview		89	15-30 days and 3 months	Patient-level and medication level adherence.	% of patients with complete adherence – and mean medication level adherence. Adherent if taking medicines as prescribed. Mean adherence % of medicines taken according to the indication at discharge.	55.1% non-adherent at first follow up; 69.6% at second follow up.
Rushworth et al. 2012 UK[163]	Face-to-face	PCI	20	Within 7 days	Quantify adherence and explore association with influencing factors.	TABS – measures adherence behaviour (ABS) and non-adherent behaviour (NABS).	6 patients had low ABS, of those 2 had high NABS.
Stange et al. 2013	Survey before at discharge		108	35-49 days	Changes in adherence at interface of care; patients'	MARS-D.	61.2% non-adherent.

Author / year	Method	Condition	Patient n=	Time since discharge	Outcome measures / objective	Measures of adherence	Rate
Germany[207]	and at follow-up. GP survey.				attitudes to medicines; GP reasons to accept or modify hospital prescriptions. Used MARS-D scale.		
Tarantino et al. 2010 Italy[184]	In hospital and follow-up questionnaire		84	1 month	Adherence rate and sociocognitive factors impacting on adherence. Age significantly associated with non-adherence. Younger patients more non-adherent. Patients more adherence to chronic medicines; adherent patients perceived more risk in not adhering and more susceptible to disease. Non-adherent patients had greater cognitive failure.	Adherent if followed the hospital schedule or subsequently change medicines (not checked).	67% adherent.
Ulfvarson et al. 2007 Sweden[185]	Structured interview	Mean age 79	200	1 week	Congruence of drug use and medical record; relationship between adherence and perceived health and perception of information received.	Adherent if taking exactly the same medicines as in the medical record.	30% adherence. 28% used less than prescribed; 42% more than prescribed.
West et al. 2010 USA[178]	Semi-structured interviews	Older women with coronary heart disease.	32	3 months	Explore adherence and identify barriers and facilitator to adherence.	Used general adherence scale of the Medical Outcomes Study. Scores 1-4 = non-adherent; score 5-6 = adherent.	65.6% adherent. Mean score 5.16.

Table 7: Studies exploring discharge medicines discrepancies and continuity

Study	N=	Average age (SD)	Condition / Focus	Data collection	Time / discharge	Outcome measures / objectives	Findings
Blennerhassett and Hilbers, 2011 Australia [167]	18		Non-English speaking	Semi-structured interviews with patients. Focus groups with clinicians	2 weeks	Explore medicines management after discharge .	Discrepancies reported between discharge summaries, GP records and hospital records.
Burns et al. 1992 UK [174]	56	82	Elderly	Home visit; questionnaire	5-10 days	Changes to prescriptions and issue of a repeat prescriptions.	15 had not had a new prescription; 14 drugs added; 17 omitted; 26 unchanged.
Coleman et al. 2005 USA [95]	375	65-85 (range)	Elderly	Home visit	24/72 hours	Prevalence of discrepancies.	14.1% of patients experienced one or more discrepancies. 50.8% discrepancies were patient-associated, and 49.2% were system-associated. Medication discrepancies were associated with the total number of medications taken and the presence of congestive heart failure. A total of 14.3% of the patients who experienced medication discrepancies were rehospitalised at 30 days compared with 6.1% of the patients who did not experience a discrepancy (P = .04).
Cochrane et al. 1992 UK [173]	50	76.9	Elderly	Home questionnaire	6-14 days	Changes in drug treatment after hospital discharge.	45 patients had a changed drug regimen. Influencing factors included incomplete drug histories; continuation of prior medicines; and errors.
Eijsbroek et al. 2013 UK [150]	21 patients / 13 carers	64.4 (13.0)	ICU	Medicines history data and semi-structured interviews	3 months	Explore medicines-related problems.	107 medicines were prescribed regularly before ICU admission, 150 were prescribed on ICU discharge, 121 at hospital discharge, and 108 three months later.8 (5.3%) chronic medicines were discontinued on the ICU and not restarted on discharge (mainly antidiabetic drugs and 1 analgesic agent). The number of medicines increased by ICU discharge, but then returned to the numbers prescribed before ICU admission – these were mainly Cardiovascular, gastrointestinal medicines, and analgesics were added by ICU and many were not continued.
Enguidanos and Brumley, (2008) USA [139]	104	76.3 (7.3)	Elderly	Survey (telephone plus physician survey and chart review)	Within three days	Number of discrepancies.	Only six cases matches between patient reports and medicines listed on the medicines sheet. The average number of medications listed in the hospital record was 4.31 (2.96) compared to

Study	N=	Average age (SD)	Condition / Focus	Data collection	Time / discharge	Outcome measures / objectives	Findings
							6.33 (4.24) reported by patients (p = .001).
Hain et al. 2012 USA[39]	103	83.2 (5.3)	Elderly	Home visit and discrepancy tool	1 week	Relationship between cognitive impairment and errors.	52% had discrepancies; association between discrepancies and cognitive impairment – 68% who had cognitive impairment had one or more discrepancy.
Mansur et al. 2008 Israel [192]	198	80.7 (7.03)	Elderly	Telephone interview	I month	The extent and reasons for modifications.	36.7% of medicines had been modified; half the changes were additions or increased doses. No correlation between change and patient characteristics. Factors explaining change were GP visits and chronic disease. Non-adherence associated with change.
Nikolaus et al. 1996 Germany [161]	119	81.9 (6.3)	Elderly	Home visit, chart review, interview	3 days; 3 months	Measure problems with containers and identify factor influencing poor adherence.	There was an increase in prescription items after discharge. 38.7% of prescription s changed within the first 3 days and 37.8% during the next three months.
Sexton and Brown, 1999 UK [166]	68 (56 patient interviews)	80.9 (62-100)	Elderly	Home interview; GP survey; documentary analysis;	2 weeks	Identify medication-related problems; accuracy of documentation; communication with GP.	32 (57%) had a drug-related problem, mostly attributable to HCPs. For 9 (13%) the discharge prescription differed from the ward prescription; for 16 (27%) patients the discharge letter differed from the TTO. GP could not find the formal discharge letter in case notes for 16 (28%). Mean arrival time with GP of 26.9 days. 55 patients obtained further supplies: 6 items stopped, 7 changed, 24 items restarted. 17 (41%) experienced side effects.
Ulfvarson et al. 2005 Sweden [189]	200	79 (6.9)	Elderly	Structured interview and record review	1 week	Congruence between hospital records and medicines use.	30% reported use in congruence with the medical record, 28% used fewer medicines than prescribed; 42% used more. Patients prescribed more than five medicines were significantly more likely to under-use (5-10 meds OR 15.9 (CI 3.3-77.8); more than 10 meds OR 10.2 (CI 1.9-55.7)).
Wai et al. 2012 Australia [193]	1319	66 (median)	Heart attack	Telephone survey, record review, GP survey	3 months	Describe baseline results from hospitals involved DMACS.	At three months there was a significant decrease in prescription of antiplatelets (p = 0.01), statins (p = 0.01), beta-blockers (p< 0.0001) and all four guideline-recommended medicines (p< 0.0001). 44% stopped by the GP (side effects or unknown). 35% of stopped for other reasons 'other reasons' were most common reason for stopping by the patient (other than cost, side effects, too many medications and confusion about duration).

Table 8: Medicines problems identified in community pharmacy after discharge from hospital.

Study	N=	Average age (SD)	Condition / Focus	Data collection	Time / discharge	Outcome measures / objectives	Findings
Paulino et al., 2004 The Netherlands[125]	435	59.1	/	Patient questionnaire	/	Explore the nature and frequency of drug related problems (DRPs) through community pharmacies and to document how community pharmacists resolve or prevent them.	451 DRPs were identified in 277 out of 435 patients (63.7%). 133 (29.5%) were about uncertainty about/lack of knowledge of the aim/function of the medicine. 105 (23.3%) were side effects. No pharmacy intervention in 66 patients with DRPs; 305 interventions in 211 patients. 80 interventions (26.2%) were to the prescriber
Ahmad et al., 2014 [127]	340	75.4 (8.7)	Elderly	Structured medication review and DRP checklist	/		992 (potential) DRPs in 340 patients For nearly all patients (95.9%), at least one existing or potential DRP was detected. Two or more DRP in 78% of patients. Number of DRP significantly associated with the number of medicines. The most common DRP identified using the checklist were 'no drugs prescribed but clear indication' and 'unnecessarily long duration of treatment'. Patients reported fear of side effects and no knowledge of drug use.

Table 9: Incidence and outcomes of adverse events after discharge from hospital.

Study	N=	Average age	Number of AEs	Number of ADEs	Avoidable ADEs	Ameliorable ADEs	Common medicines or problems	Risk factors
Gray et al. 1999[48]	256	80		52 (20%)			Cardiovascular (19%) although high level of use; Antibiotics (17%); CNS (16%); Endocrine (16%); Analgesic (12.5%). CNS highest rate of ADE within drug class (11.8).	Females (OR 2.26, CI 1.06-4.77) Interaction of number of new medicine and cognition.
Sexton and Brown, 1999[166]	43			17 (41%)			Antibiotics, diuretics, analgesics.	
Forster et al. 2003[47]	400	57	76 (19%)	50 (66% of AEs)	12 (50% of avoidable AEs)	19 (76% of ameliorable AEs)	Antibiotics (38%); corticosteroids (16%); analgesics (10%); anticoagulants (8%).	Provider-patient and provider-provider communication found to be the main problem.
Forster et al. 2004[50]	328	71	76 (23%)	72% of 76			Antibiotics (27 patients); concomitant use of interacting medicines; contraindications; failure to monitor treatment.	Risk factor of AE: Female (OR 2.3, CI 1.3-4.1), Type II diabetes (OR 1.9, CI1-3.6); pneumonia (OR 1.9, CI 1-3.6).
Forster et al. 2005 [51]	400	57		45 (11%)	27% (of 45)	33% (of 45)	Anti-infective agents (31%); corticosteroids (16%); analgesics (11%); anticoagulants (9%); antiepileptics (4%).	Number of medicines; recall of medicines side effects being prescribed.
Marusic et al. 2013 [198]	222	72 (median)		19 (8.5%)			ACE inhibitors	190 had potential DDIs, 21 (9.5%) had actual DDIs. ADEs occurred in 19 patients (8.5%), with ACE inhibitors being the most common medicine in instances of ADEs.
Bennet et al. 2014[197]	204	80.5 (+-8.3)	119 (58%)				Falls, hospitalisation, institutionalisation and functional decline. Adverse outcomes more common in the frail sample.	FRIDs (OR 1.7; CI 1.3-2.1) and number of medicines at discharge (OR 1.2; CI 1-1.3) associated with recurrent falls. FRIDs (OR 1.3; CI 1.1-1.6) and number of medicines associated with functional decline (OR 1.1; CI 1.0-1.2). Number of medicines associated with hospitalisation (OR 1.1; CI 1.0-1.2). FRIDs associated with institutionalisation (OR 1.3; CI 1.1-1.6).

Chapter 3 – Methodology

This chapter sets out the design of the research studies described in this thesis, the rationale for the methodological approach adopted and describes the methods used. It sets out to demonstrate how the methods chosen were able to explore patients' experiences of medicines management and were appropriate to the clinical settings, the patients themselves, who had experienced a health crisis, and to the researchers' epistemological position.

3.1 Study design

The research in this thesis study was designed in the following stages:

1 A structured narrative review of the literature to form an evidence base of how patients experience discharges medicines management. This was reported in Chapter 2.

2a A two-centre prospective, descriptive study to establish how UK NHS hospitals discharge cardiology patients with medicines. This second stage used a mixed method design to collect observation data about how patients experienced medicines management at the point of discharge from hospital. A patient safety framework was applied to analyse the observation data. The results of this study are described in Chapter 4

2b A two-centre prospective, descriptive, parallel mixed methods social network analysis to establish how UK NHS patients experience medicines management after they are discharged from hospital. This stage comprised four components: patient diaries; semi-structured interviews; network mapping; and a medicines experience survey. The first three components were designed to collect relational data so that a social network analysis framework could be developed and applied. The results of this study are reported in Chapters 5–7.

The overall study design is presented in Figure 6.

Figure 6: Study design scheme

The foundations of this research are embedded in the researcher's interest in how the social world – the form of social contacts that the people experience – impacts on medicines experiences and roles after leaving hospital. A preliminary literature search indicated that very few studies took this into account. The studies subsequently identified and discussed in the literature review in Chapter 2 generally did not focus on understanding the social context

in which medicines are managed. Instead, study designs concerning medicines adherence and adverse drug events have broadly taken a deterministic approach to empirically measuring phenomena such as medicines adherence or whether patients understand their medicines or have experienced harm from them. I am critical of such designs because they do not explore aspects of patient experience, such as the processes through which they have contact with healthcare professionals, the organisation of healthcare in their area and the level of immediate help and ongoing support each individual can access. This study is concerned with addressing those gaps. It is also concerned with exploring the medicines management system at the point of discharge in hospital, which may or may not influence how patients experience the system and how it supports their optimal medicines use once they are discharged. The challenges of doing this within a single paradigm are discussed in this chapter. First, the researcher's epistemological position is discussed.

3.2 Epistemology

Ontology is a philosophical or metaphysical concept which is centred on questions of existence and truth, e.g. what is existence? Is there a supernatural God? Epistemology is concerned with the methods one might employ to investigate such truths, the nature of knowledge and its legitimacy.[208] Competing ontological theories mandate epistemological positions for research and set out the relationship with the methodologies and methods used.[209] Bryman describes two of the main ontological orientations that influence researchers' epistemological positions:[210]

Objectivism – The researcher objectively studies the social world which exists independently of the people who live within it.

Constructivism – The researcher studies the social world and its members as a social construct, rather than as a real phenomenon. Those within the social world constantly modify it.

This research takes a constructivist approach, accepting that patients and healthcare professionals act within a constructed reality that they create and modify through their contact with others and their experiences. It rejects the more traditional objectivist position that there is a social reality independent of those being researched, and that can be measured empirically.

As presented in Figure 7, various positions have emerged and competed to influence how research is conducted and appraised**.** Positivism, based on an objectivist epistemology was the dominant research perspective in the 20th Century.[208] It asserted that research findings and any associated inferences can be measured, objectively assessed, and that causal relationships can be identified. The researcher is viewed in a role upholding objectivity; the related methods tend to be experimental and quantitative. Post-positivists, however, rejected the certainty and objectivism of positivism by asserting that inferences can be made based on the combination of theoretical reasoning and evidence informed by experience.[211] Emerging from post-positivism are the different theoretical perspectives that guide research design and methodological approaches. Critical inquiry challenges the power dynamic in society and traditional mainstream research practices. Interpretivism, as part of the constructivist orientation, focuses on people's subjective interpretation of the social world and the part they play in it. Again, both qualitative and quantitative data can used to explore and interpret subjective experiences. According to Angen:

"Interpretive researchers assume that reality as we can know it is construed intrasubjectively and intersubjectively through the meanings and understandings garnered from our social world."[212]*(p385)*

According to McKenzie and Knipe, interpretivist/constructionist researchers will sometimes use mixed methods approaches (combining qualitative and quantitative research) arguing that *"no one paradigm prescribes or prohibits the use of either methodological approach"*.[213]

The research in this thesis has adopted an interpretivist approach to explore the patient experience of the medicines management system. The analysis of patients' medicines management ego-networks in Chapters 4–6 adopts an interpretive approach. In collecting primary data, I have worked with research participants to interpret how the system impacts on their experiences. The research combines a mixed-methods social network analysis with mixed methods observation research, which has been pragmatically informed by the complicated nature of the clinical environment and practical problems of researching it, such as the unscheduled nature of some healthcare activities, for

example discharge from hospital. In this approach, the research methods chosen are aligned to the problems or questions being considered.[214]

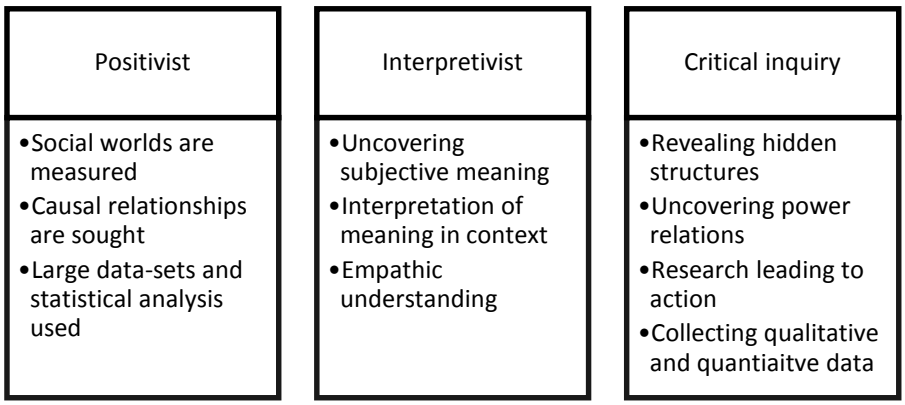


Figure 7: Theoretical positions from Matthews and Ross (2010)[215]

Blaikie identified four types of research strategy which are presented in Figure 8: inductive; deductive; retroductive; and abductive.[216] Inductive and deductive strategies are the most widely used and so warrant closer examination. Inductive strategies involve collecting data to explore and understand relationships between variables, whilst deductive strategies collect data to test hypotheses typically using an experimental or quasi-experimental design. Those critical of inductive strategies argue that researchers are naturally biased and so collect and analyse data they consider to be important. Deductive strategies are judged in part problematic because they can inhibit creativity in research because theories are pre-defined.[216] This research applied an combination of inductive and deductive strategies to both describe and interpret patients' experiences.

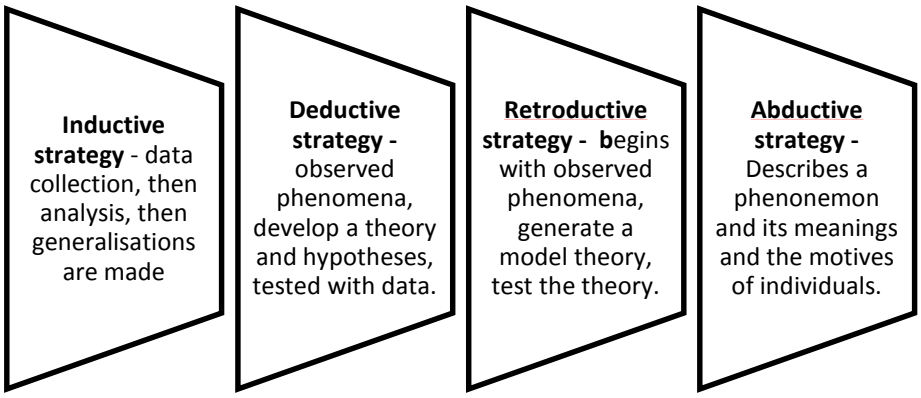


Figure 8: Research strategies from Blaikie, 2000.[216]

The next section will explore the principles behind adopting a mixed-methods research design and the rationale for using mixed-methods in this research.

3.3 Mixed methods research

Mixed methods research combines both quantitative and qualitative approaches either sequentially or simultaneously.[217] It is thought that the concept of mixing methods was formalised in the late 1950s and further developed in the 1970s.[218] One of its key strengths was considered to be its ability to reduce bias through triangulation of different sources of data.[219] It is criticised by some based on the two different paradigms in which quantitative and qualitative research are embedded. Others, however, hold that whilst the two different types of data are underpinned by different epistemologies, that underpinning is not necessarily fixed.[220] Cresswell and Plano Clark argue that the combination of the two data types offers a better understanding of research problems.[217] They identified six different types of mixed methods projects – shown in Figure 9 – which collect and analyse data in different sequences. Combining these different data types increases the depth of understanding into key concepts and is a form of methodological triangulation, allowing different perspectives on the same social phenomena and a more substantive view, yielding a stronger research design.[221]

The first observation research study in this thesis, described in Chapter 4, adopts a convergent, parallel mixed methods design to maximise efficiency through concurrent data collection, which is essential in the clinical setting where patient discharge timing is unpredictable. The second study, described in Chapters 5–7, is a parallel, mixed-methods social networks analysis, simultaneously collecting structured social networks data and qualitative network data.

More information about mixed methods social network research is detailed in Section 3.6.9 in this chapter. In general, however, five key principles for mixing methods in social research have been adopted and applied: a flexible approach to research design; a questioning and reflexive approach about both the quantitative and the qualitative research paradigms; recognising that the different approaches are valid; a reflexive approach to interpreting the data; and

incorporating rich explanations that can include quantitative interpretation.[222] In this research qualitative and quantitative approaches are integrated using these principles, recognising that the complementary nature of each method can yield positive outcomes to research which examines real-world problems and that mixing methods increases the capacity of the research to enlighten the *"processual nature of social events and interactions"*.[223(p86)] The mix of methods used and their underpinning is outlined in Figure 10.

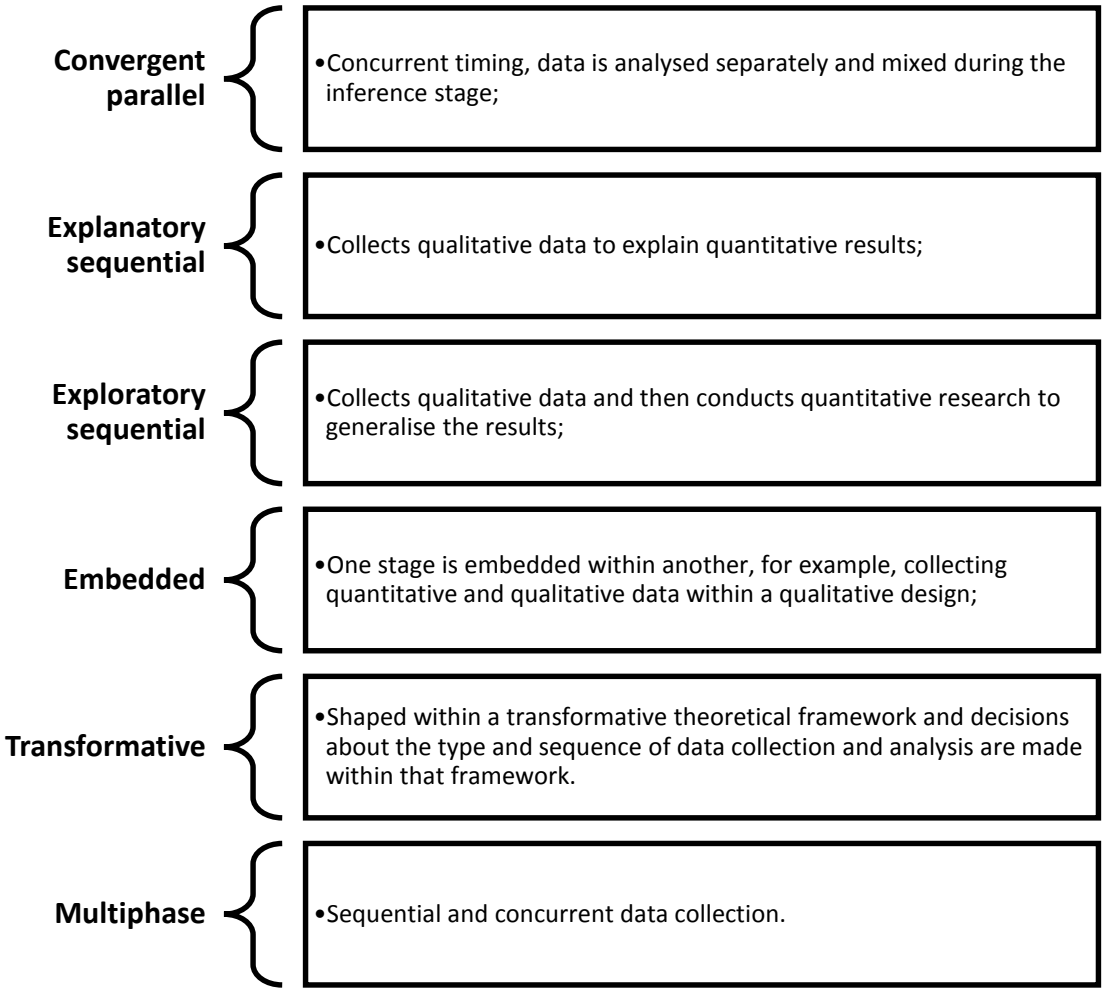


Figure 9: Six approaches to mixed methods from Creswell and Plano-Clark

This section has set out the underpinning theories informing the research. The following section will describe the range of methods used in each of the studies, their strengths and weaknesses, and the alternative methods that could have been employed. It will also explain the study setting used and the choice of patients and their health condition.

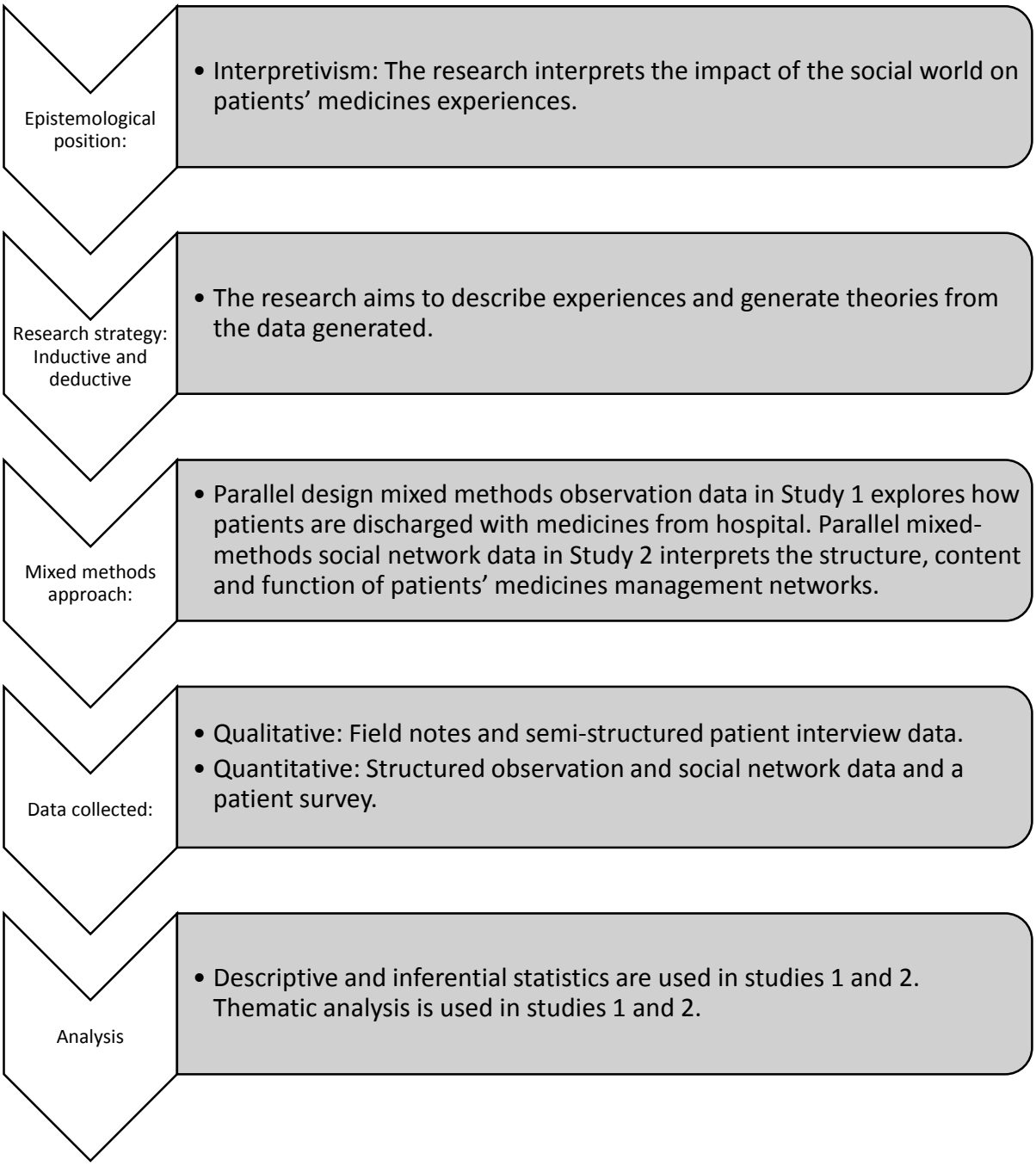


Figure 10: Outline of the mix of methods used in the study.

3.4 Methods

This section begins by describing the research settings before moving on to describe how the patients' health condition was selected and then to the design of each individual study.

3.4.1 Study settings

The studies described in this thesis were conducted with patients from the cardiology wards of two acute hospitals in different regions of Northern England.

This section gives some background about the study sites, the regions in which they are sited, and their local populations. Data about population and health outcomes are taken from the 2014 Public Health England Health Profiles.[224] Health outcomes for each area are presented in Table 10.

3.4.2.1 Site 1

Site 1 was a 900-bed hospital forming part of an NHS teaching hospital foundation trust serving a population of approximately 0.5 million people in 100,000 households. The trust employed approximately 5,000 people across several hospital sites. It had an annual income in 2014 of £364 million. Over 40% of residents lived in the most deprived national deprivation quintile. According to Public Health England, over a quarter of adults in the areas were classified as obese (26.7%) and smoking related deaths were worse than the English average. Early deaths (people under 75 years of age) from heart disease and stroke had been consistently higher than the English average: in 2010– 2012 there were 107.7 early deaths from cardiovascular disease per 100,000 people aged under 75, compared to 81.1 nationally. Emergency admission to hospital rates were slightly higher than the national average.

3.4.2.2 Site 2

Site 2 was a 690-bed hospital which forms part of a NHS trust, again serving a population of just over 0.5 million people. The total workforce in the trust was in excess of 7,000 people and it has an income of approximately £420 million. It covered the populations of several different unitary authorities and districts, most of which are highly deprived: nearly half the population of area 1, for example, were in the national deprivation fifth quintile (most deprived); and the under-75 mortality rate for cardiovascular disease in area 4 was 121.8 deaths per 100,000 people, compared to 81.1 nationally. Indeed, in all but one area served by the site, life expectancy for men and women was lower than the national average and the rates of cardiovascular disease and obesity were higher than the national average. Emergency admission to hospital rates varied within the different areas, but were generally higher than the national average.

3.4.2.3 Selecting the patients' health condition

Cardiology patients were chosen as the focus for both studies for a number of reasons, not least because there are evidence-based therapies that when

managed optimally can contribute to the long-term management of cardiovascular disease;[225–227] Furthermore, in the UK, cardiovascular disease is responsible for approximately 30% deaths annually;[228] and it has a serious impact on the quality of life of those who live with the disease.[229] Because of the wide ranging impact of cardiovascular disease, improving the UK's performance in managing it is a key government priority.[228]

3.5 Study 1 – Observation research

3.5.1 Aims and objectives of Study 1

This research is a convergent parallel mixed methods study of discharge from cardiology wards.

Aim:

- To determine how patients are discharged with their medicines from two hospital sites.

Objectives:

- To explore the context and content of staff-patient interactions about cardiology medicines prescribed and provided to patients at discharge.
- To explore the contributory factors to preventable harm to patients when they are given their medicines at discharge.

3.5.2 Introduction to observation research

Observation research is a non-experimental research method allowing the researcher to generate data about current practice in its natural environment. Data are collected at the point that they are generated by the subjects under investigation.[215] The roots of observation as a research method are grounded in multiple approaches including anthropological research (unstructured observation), and natural and laboratory based research (structured observation).

Observation can be participatory, where the researcher may become a member of a group that is the subject of the research and non-participatory, where the researcher remains outside the group being observed and studies their actions. In this case, in a ward setting with a non-clinical researcher, a non-participatory approach was adopted.

Table 10: Health outcomes for the regions served by the two hospital sites. Data compiled from Public Health England Health Profiles 2014[224] and Office of National Statistics population estimates 2014.

Region	Population	Deprivation (% people living in the 20% most deprived areas of England)	Premature death rate from CVD (per 100,000)	Proportion of adults obese %	Emergency admission rates %	Life expectancy women	Life expectancy men
England	53,900,000	20.4	81.1	23.0	40.8	83.0	79.2
Site 1	526,000	45.1	107.7	26.7	40.3	81.5	77.5
Site 2 area 1	148,000	52.4	121.5	26.3	46.6	80.9	76.5
Site 2 area 2	68,000	19.1	99.4	25.5	41.6	81.6	77.6
Site 2 area 3	90,000	38.2	96.4	25.3	40.8	81.7	77.9
Site 2 area 4	87,000	49.4	121.8	24.3	45.0	80.5	75.5
Site 2 area 5	58,000	0	74.3	18.6	36.4	84.0	80.5
Site 2 area 6	80,000	41.5	109.3	27.7	44.7	81.0	76.5

Critics of observation as a research method argue that the decisions about what to record and the analysis of the data are influenced by the researcher's perceptions of what is important. One of the strengths of observation compared to other approaches, such as face-to-face interviews, is that it collects data as the phenomenon occurs, rather than in retrospect, and it reduces the bias created by the researcher directly imposing their own social world on the phenomena being studied.[230] Patient and staff accounts may also be subject to bias based on their perceptions of their limited role in the whole context of a system rather than of the system itself.

An observation approach was selected to generate mixed qualitative and quantitative data about how hospital healthcare staff discharge patients with medicines from hospital. It was designed to understand the context in which patients leave hospital with medicines to offer a richer interpretation of the grounding of their experiences after they leave hospital. It was felt that this type of data could not be obtained through alternative research methods. Observation as a method affords this study a means of generating data about interactions with patients about medication at discharge because it overcomes the bias inherent in recalled accounts.[231] Furthermore, the researcher can clearly directly witness the naturalistic setting, rather than relying on retrospective accounts. In addition, and with specific reference to the topic of this study, the day of discharge can be a confusing and anxious time for patients;[144] and they may not be able to remember the different interactions they had with multiple healthcare professionals and the content of those interactions if asked at a later date. For example, patients in one previous research study in the 1990s reported that they had not received any information about their medicines, however observations in the same research indicated that they did receive structured medicines information at discharge.[145]

3.5.3 Overt and covert approaches

It is generally accepted that covert observation approaches – ones where the subjects of the observations are unaware that they are being observed – are difficult to justify ethically. Those who champion covert methods argue that participant knowledge of the observer's presence would bias the results and that sometimes the phenomenon being studied is difficult to observe overtly, for example if it is illegal. Overt participation, on the other hand, may lead to the

subjects adapting their behaviour because of the presence of the researcher. The four types of observation research (adapted from Gold's 1958 typology) are presented in Figure 11.[232] Complete observation and complete participation are only possible using covert methods, which are often ethically questionable. Additionally, complete participant and participant as observer roles in this clinical environment would require the researcher to be a clinician involved in patient care. More detail is offered by Bryman who goes on to outline six different observation roles, which are presented in Figure 12.[210] This study adopted Bryman's non-participating observer with interaction approach. This approach accepts that the observer was not involved with the team delivering patient care and consequently interaction with staff and patients was limited, however, because of the long periods of time spent observing and waiting for discharges to occur, some interaction with both staff and patients naturally occurred.

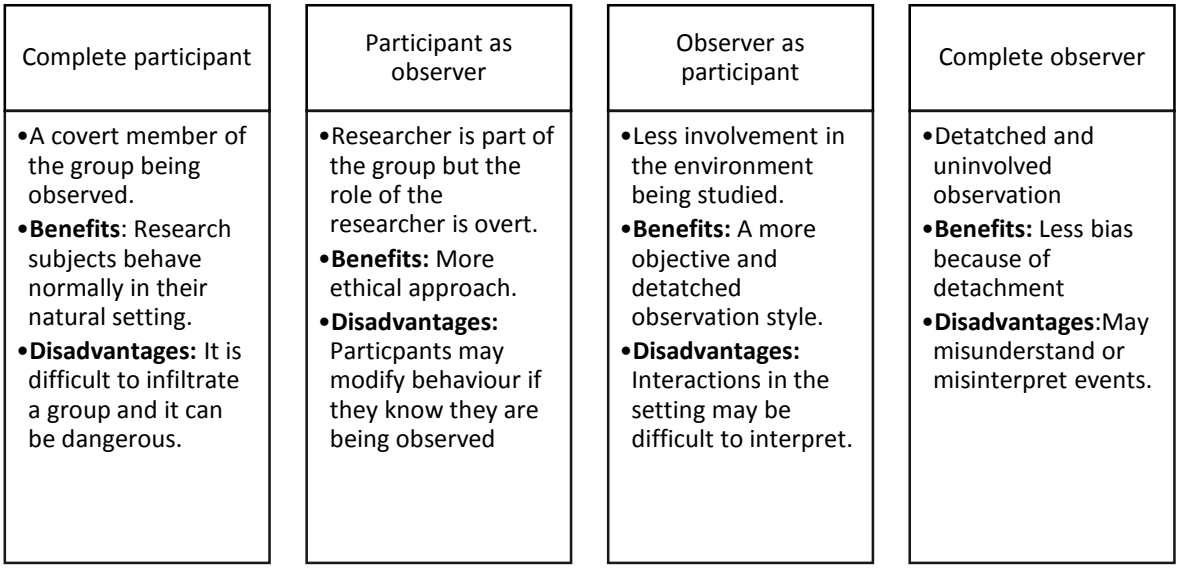


Figure 11: The four types of observation research. Adapted from Gold.[232]

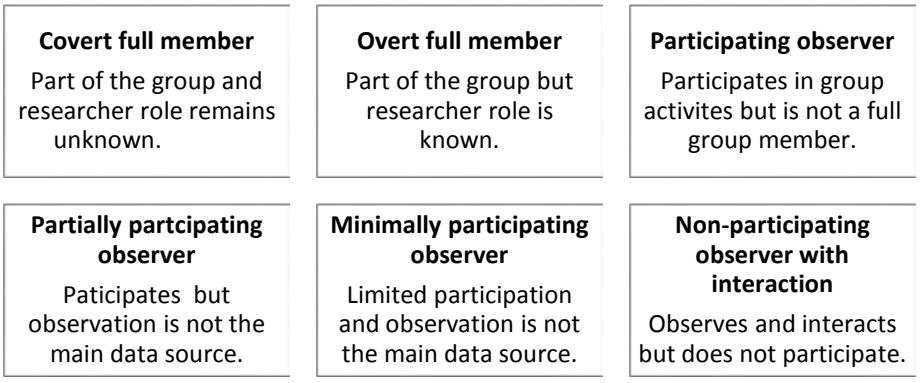


Figure 12: Observer roles from Bryman.[210]

3.5.4 Structured and unstructured observation

Structured observation generates quantitative data through observational schedules that record the frequency of events or behaviours using predetermined categories. This approach requires the researcher to participate less in the environment being studied. It allows the researcher to collect data that can be replicated in different places, at different times and also by different researchers.[208] However, critics of this approach claim it overlooks the context in which the data is collected, in this case the hospital environment, and that it imposes assumptions on the setting and overlooks the complexity of that setting in the analysis and as a consequence, the researcher may impose an inappropriate coding framework.[210] Structured observation requires the researcher to pre-determine and categorise the focus of the research in order to create variables for a quantitative analysis. Qualitative data is collected during unstructured observation through narrative field notes, which then are subject to processes of data reduction, data display, conclusion drawing and verification. Through these iterative processes data are selected and extracted, organised into narrative text, explained and confirmed for their plausibility.[233] In this study, a combination of structured and unstructured observation was used, and a comparison of the methods is shown in Table 11.

Table 11: A comparison of observation approaches from Bryman.[210]

Structured	Unstructured
Pre-determined categories and schedules	Field notes or recordings taken by the observer
Pre-specified procedures	Limited pre-defined procedures
Concentrates on the observable behaviour of the research subjects	Able to observe events as they happen outside the window of observation
Breaks analysis down into units of action	Sees the context as a whole

3.5.5 Designing the observation schedule

An observation schedule was constructed (See Appendix 2) which allowed the researcher to note what staff explained during the discharge, including:

- The purpose of the medicines, for example what conditions they are for, and what their intended effect is.
- Side effects the patient may experience, for example fatigue, headaches, muscle cramps.
- How medicines should be taken, for example orally or via a spray.
- Dose information, for example the number of milligrams per dose.
- Frequency information, for example once per day or twice per day or as required.
- Timing information, for example the time of day it should be taken.
- Hospital communication with primary care, for example whether information about medicines would be sent to the patient's GP practice.
- Obtaining repeat medicines in primary care, for example how to go about getting a repeat set of medicines once the patient has left hospital.
- Giving written take-home information, for example if the member of staff gives the patient a list of their medicines and information about changes.

Items on the schedule were devised based on previous research indicating that patients' preferences for medicines information include the purpose of the medicines, side effects, the 'dos and dont's' and how to take them.[234] Indeed BMA guidance stresses the importance of patients being aware of the medicines they are taking, what they are for, associated side effects and how to take them.[235] Previous research has also found that patients did not receive a written list of their medicines;[144] and the BMA guidance stresses the importance of timely communication between care providers and how patients often are in receipt of information about their condition before their GP.[235] Information about how to obtain further supplies – along with purpose and side effects – is an item on the validated Satisfaction with Information about Medicines Scale;[236] indeed, the patient representative involved in this study documented several problems inherent in the process of obtaining repeat prescriptions.[237]

Schedule development followed best-practice guidelines including ensuring a clear focus for what and who is being observed and an easy-to-operate coding system.[210] Data were systematically recorded.

3.5.6 Sampling

Sampling approaches can be time based – for example observing for structured time periods – this would not have been feasible for this study as its focus was the act of discharging patients and a time-based approach would have failed to yield data if no discharges took place within the allocated time. Sampling can also be event based, which for this study was considered a more appropriate approach because the patient discharge was a milestone event in their care. In advance of the study, the researcher was unaware of the number of patient discharges it would be possible to observe. This necessarily gave rise to an emergent sampling approach which allowed the researcher to make decisions about the sample as the research progressed. The researcher undertook to attend the wards on randomly selected days and continued to do so until theoretical saturation had been reached and no new phenomena were observed.[238]

3.5.7 Data collection

The researcher recorded the name of the medicine on each occasion and also the amount of time the discharge took. It was documented whether the staff member solicited questions from the patient and if staff were asked questions and the nature of those questions. One observation sheet was used to record one staff and patient interaction. The reverse of the sheet and continuation sheets were used to make detailed field notes about the interactions, for example the length of the interactions or if carers or relatives were present, actions of staff, rapport between staff and patients and problems experienced. Observations took place on weekdays between 8.30am and 5pm. When the researcher arrived on the ward a consultation with the ward manager established which patients might be discharged that day. The researcher approached patients to explain the study and ask for their consent to take part. This process is detailed in section 3.7. The researcher explained the study to staff working on the ward and took the appropriate consents (see section 3.7). The researcher would then ask to be informed if staff were going to undertake discharge-medicines related activities with the patient so it could be observed.

At Site 1 each patient was listed on a series of white boards positioned in the central ward area. If the patient was due to be discharged that day a mark (‘D’) would be put by their name on the board. Staff would usually then try to transfer

patients to the hospital's 'discharge lounge', which was on a different level on the site and at some distance from the ward. Staff would inform the patient that they were being transferred and, if the patient did not object, they would telephone the discharge lounge and a healthcare assistant would be sent to collect the patient and their notes and transfer them. In practice this added an additional transfer of care from the ward to a different hospital department in advance of the transfer of care to primary care. Some nurses were permanently based in the discharge lounge which was managed by a nursing sister. Observations, therefore, took place in the discharge lounge at Site 1 if cardiology patients were transferred there, whilst some patients remained on the ward and were discharged from there. During the data collection period, wards at Site 1 were encouraged to send as many patients as possible to the discharge lounge and internal recognition was given to those wards which transferred the most patients. Because the time and location of the discharge were unpredictable the researcher spent time on the ward and in the discharge lounge taking notes about how the discharge medicines system appeared to operate. Staff in all locations also informed the researcher if they were about to counsel a patient. Ward-based nursing staff were cardiology-specific whereas those located in the discharge lounge had a more general background.

At Site 2, a three-tick system on a white board tracked the discharge process and acted as a means of internal ward communication about completed actions. Patients due to be discharged each day would be listed on the white board and a series of ticks would be added to their names at different stages of the discharge process. One tick indicated that a prescription for the patient's to-take-out (TTO) medicines had been prepared; a second tick indicated that the prescription had been reviewed and validated; and a third tick indicated that the medicines were prepared and the patient was ready for discharge. Again, because the time of discharge was unpredictable the researcher spent time on the ward taking notes. Staff informed the researcher if they were about to speak to the patient about their medicines and, similarly to Site 1, some nurses were observed discharging patients on more than one occasion, whilst others were observed on single occasions. Site 2 had a permanent ward-based pharmacist and a supply room of some medicines that were regularly prescribed on the ward. Part of the ward pharmacist's role was to prepare TTO medicines, or

order those not available on the ward from the dispensary, and talk to patients about their medicines before they left the hospital. At this site all patients were discharged from the ward.

3.5.8 Data analysis

Data were analysed using two distinct methods: structured observation data were analysed using descriptive statistics and non-parametric tests, whilst qualitative field notes were analysed using a human factors framework.

3.5.8.1 Structured observation data

Structured observational data (e.g. the type of medicine and the content of the discharge) were recorded in a SPSS database and analysed descriptively. Any differences between hospital sites and between medicines were explored using Kruskal-Wallis and Pearson's chi-squared non-parametric tests.

3.5.8.2 Qualitative observation data

Qualitative data in the form of field notes were analysed using the Yorkshire Contributory Factors Framework (YCFF), which is a 19-domain framework of contributory factors that could contribute towards patient safety incidents (see Figure 13).[30] It was developed from a systematic review of the analysis of patient safety incidents. A patient safety incident is any unintended or unexpected incident which could have or did lead to harm for one or more patients receiving NHS care.[239] Field notes were analysed and phenomena observed were grouped together and described under each of the domains. Whilst the YCFF was developed specifically to look at contributory factors that could contribute to a patient safety incident, this study also took into account the context in which patients might use their medicines after leaving hospital and the processes that might affect their ability to safety manage their medicines after their discharge.

3.5.9 Limitations of the study design

There are several criticisms of observation research as a method. One often cited limitation is its vulnerability to observer / reactive effect: participants may behave differently because of the presence of the researcher, described by Webb et al. in 1966 and restated by Bryman and often referred to as the Hawthorne effect.[210] There are four components of the reactive effect:

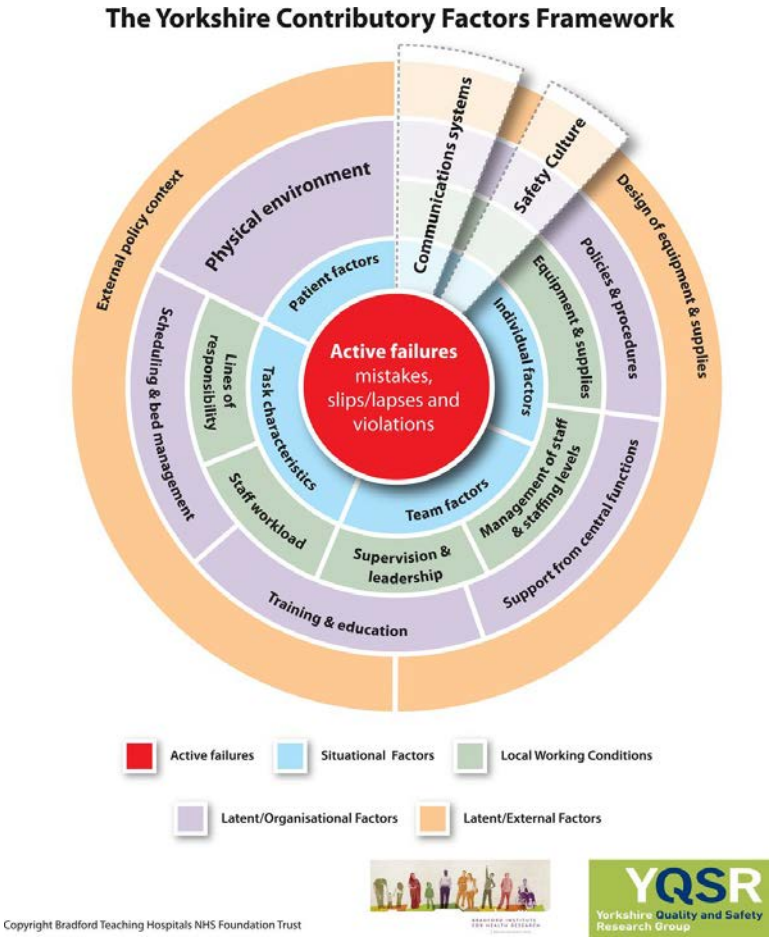


Figure 13: The Yorkshire Contributory Factors Framework.[30] Reproduced with kind permission.

- The subject may try to adopt a specific role or style, for example they may adjust their behaviour in line with what they perceive to be the study aims. In the case of this study, a staff member may misconceive the research to be about counselling styles and subsequently adopt a particular style they may think advantageous. The researcher saw no evidence that staff adapted their behaviours in this way.
- The researcher affects the environment simply by their presence, for example taking up a seat on the ward may fundamentally change the physical layout of the ward or take up space usually used by a staff member. The researcher thereby becomes a 'change agent'. The researcher was aware of this potential threat to the research and undertook to limit their impact on the day-to-day running of the environments under observation.
- The participant consistently and inappropriately adapts how they respond, referred to as 'response set'. The original study protocol for the research had acknowledged that this was a potential issue and the researcher took

care to inform staff that they individually were not being scrutinised; rather it was the system they worked within. Despite this, some staff members asked the researcher how they had performed so it is possible that their awareness of being observed led them to adapt their behaviour. However, the researcher observed wide-ranging practices so it is unlikely that all participants were able to change their behaviour to achieve a form of 'best-practice'. Alternative methods may have produced data about the reasons staff conducted discharge medicines management in the way they did, however, this would not have yielded the naturalistic data thought necessary to describe what patients experience when they leave hospital.

- The WHO warns that observation of healthcare providers may be perceived as a threat.[240] Participant information sheets were drafted to be clear that the observations were about the systems in place, rather than the actions of any individual staff member.

This section has described the methods used in Study 1 of this research, including the range of data collection tools developed or employed and the context that data were collected in. It has also critically reflected on the appropriateness of those methods and the alternative methods that might have been used. The following section will outlines the methods designed for Study 2.

3.6 – Study 2: Patients' medicines management ego-networks

3.6.1 Study 2 aims and objectives

Aim:

To understand how patients experience post-discharge medicines management.

Objectives:

- To identify the range of healthcare professionals and support staff who patients interact with after their discharge from hospital.
- To explore the contribution of patients' own personal contacts to discharge medicines management ('hidden' system components).
- To understand the functions provided by different network members and the value placed on those functions by patients.
- To visualise patients' networks to better understand the extent of variation between different patients.

- To measure patients' experiences with their discharge medicines and explore variables associated with those experiences.

3.6.2 Social network analysis as a research methodology

Social network analysis (SNA) grew from two separate traditions: sociology exploring group processes; and anthropology exploring complex societies.[241] It is applied to understand how outcomes and future characteristics may depend in part on the structure of personal or organisational networks.[242] Previously defined as a *"specific set of linkages between a defined set of persons"*[243(p2)] it aims to visualise those linkages, usually using graphing techniques such as sociograms, measure them, describe them and model them. Modelling the networks can help predict the impact networks have on outcomes; and the nature of linkages between people can be used to interpret people's behaviour.[243] The unit of analysis can be the "network" of linkages itself or the linkages between people, which are often termed "network ties". Analysis of the networks of individuals (ego-networks) rather than groups explore how individuals are influenced by their social ties.[244] Types of "network ties" between people in networks are in four basic groups: *similarities*, for example co-location, or similar genders; *social relations*, for example, being someone's colleague; *interactions*, for example seeking advice or help; and *flows,* for example information or knowledge flows between individuals.[242]

The focus on interactions *in the social world*, rather than attributes, such as demographics, is the quality that sets SNA apart from the methods used in more traditional empirical epidemiological studies. Those that champion SNA argue that those studies mistakenly ignore the structure of interactions and relationships and the impact of those structures on people, organisations and outcomes. In Pescosolido's work on how social network theory and analysis can be integrated into the health sciences, she described how overlooked factors often take on the *"flavour of luck"* and how the patterns and predictability of people's social world are ignored. She argues that *"the underlying engine of action is real human contact."* [245(p194)]

Networks are built by people's interactions which can restrict or facilitate access to resources and services, such as medicines information, and create cultures, beliefs and behavior patterns.[245–247] People may also use their networks to

understand their health conditions and use the information they gain from people in their networks to make decisions about their health and their medicines.[248,249] Thus the nature, frequency and value of interactions between patients and the people they interact with – not just attributes such as age, gender and ethnicity – can affect patient outcomes, such as morbidity and mortality.[250]

3.6.3 Whole networks and ego-network approaches

There are two distinct types of social network analysis. Whole (socio-centric) networks explore interactions between people in a bounded group, such as all those who work within a community pharmacy, or within geographically bounded areas, for example all community pharmacists working within a district. The ego-centric (or person-centric) approach explores the impact of the social context on the outcomes of individuals. The ego-centric approach is appropriate when the population of interest does not exist within a bounded social context. Ego-centric approaches collect data on the social relations of the 'ego' (the person of interest) and the relations between their 'alters' (the people they have social relations with). Using an ego-network approach rather than a whole network approach allows exploration of the experiences of many people rather than just the few patients that a whole network approach could include. The resources required to document the whole networks for many patients would have been beyond those available to the researcher.

Ego-networks allow us to see the network as the patient views it. This type of perceived social structure allows a view of the system as the patient experiences it and interprets it,[251] rather than how it is designed to be delivered. This places the patient in the role of the "perceiver" of the relationship. Ego-networks are ideal for this study as they allow a total focus on the individual, rather than on organisations. They allow us to take into account the multiple types of formal or informal ties that people form in their *experience of* healthcare, rather than just those that form between professionals in the *delivery of* that care. It allows us to view the patient's actual world and their real situations, exploring how medicines interaction occurs within those worlds both in formal settings and away from formal patient-provider contexts. Above all, putting the patient in the centre of the networks makes sense against a backdrop of increasing interest in patients' role in enhancing system resilience.

3.6.4 Social Network Analysis and the safety and quality of healthcare

Since 2000 there has been an increase in the number of published studies using SNA across a range of disciplines.[252] Notably of late, it has been used in health services research to examine relationships between healthcare professionals and between professionals and patients.[253,254]

Previous social network studies have concluded that social relationships impact on people's health outcomes. In their landmark study, Berkman and Syme's 1979 work demonstrated that four different sources of social relation (being married, having contact with friends or relatives, belonging to a church and being members of groups) impact on the risk of mortality.[255] Those who lacked social ties, and were therefore isolated, were more likely to die earlier, after controlling for other factors, than those who were more connected. There is also a range of studies that have explored the impact of social support on health outcomes, including adherence to medicines.[256] More recently, work has explored the impact of social networks on managing chronic illness.[257]

Studies of social networks in the healthcare domain involving service providers have explored the structural relations between HCPs, the social context of HCPs, partnerships and knowledge sharing.[254] Research on the effectiveness of team delivery of medicines safety has primarily focussed on the experiences of healthcare providers and their interactions and interventions. For example social network analysis has been used to explore how teams in hospital settings work together to make decisions about medicines,[258] however, their work did not focus on the agency of the patient in that setting.

Only one published study identified has used SNA to look at the patients' perspectives on the structure of collaborative healthcare relationships that include community pharmacists.[249] It aimed to understand the patients' roles in multi-disciplinary asthma care, described and compared patients' health networks, gained an understanding of their interactions, and identified the pharmacists' roles within asthma patients' networks. The study used a mixed methods, embedded design involving patient interviews (n=47), personal network diagrams and asthma-related questionnaires. Two different patient groups were identified and compared: 26 participants who attended community-based asthma groups; and 21 participants who attended asthma clinics. The

researchers found that patients do not experience joined up multidisciplinary care and they view the community pharmacist to be on the periphery of their condition-management networks. Whilst a concern with patients' perceptions of the quality of their collaborative care and the role of the pharmacist is evident in the study, there is no direct focus on the safety of their care or the system within which they use their medicines. More recently, Cheraghi-Sohi et al. explored how personal network members influenced medicines-taking amongst 20 people with long-term conditions.[247] The authors used the concept of 'medicines work' to explore the roles of others in enabling medicines taking. They found that personal network members performed tasks such as collecting and monitoring medicines, offered emotional support, and provided information to patients.

3.6.5 Structure, content and function

When examining social networks the three main measurement features of interest are *structure*, *content* and *function*.[245,248] Network *structure* is the architecture of the network. Measures of structure include the size of the network and the density of the network, which is the proportion of possible connections in the network that are made. The *content* in the network is the nature of flow between people, i.e. material and non-material resources.[241] Content could be friendship, advice, information and communication. The *function* of the network is its purpose, for example protecting patients or caregiving.

Kjos et al. used SNA to explore patients' medicines information-seeking behaviour.[248] In this study, the *structure* of patients' networks was defined as the people the patient derived or sought medicines information from, its *content* was medicines information in the form of factual information, attitudes and beliefs about medicines information, and its *function* was the patient's application of the information they received. The study used qualitative techniques comprising 40 semi-structured interviews in a range of settings. Lay and professional contacts were identified: professionals offered factual information, whilst lay contacts provided factual information, beliefs about medicines and attitudes towards them. Patients used information from both types of sources in similar ways. Whilst the study concluded that HCPs should be aware of the patients' social environment so that they can align their role

with it, it is unrealistic to expect a provider to do this. Rather, providers should be aware of where patients lack factual information about their medicines to negate their need to seek it from ‘unsuitable sources’.

3.6.6 Formal and informal ties

By exploring patients’ medicines management ego-networks this study will describe the extent to which patients benefit from the formal professional and inter-professional ties in the healthcare team around them and from the informal ties they have to others such as family members or friends, who might be considered ‘hidden’ components of the medicines management system. Research into health social networks has categorised ties as either ‘formal’ and ‘informal’;[248] or other such categories, for example ‘family’ and ‘HCP’.[247] Formal ties are those with health services providers, for example healthcare professionals, and informal ties are those with family, friends and more distant informal contacts such as friends of friends.

3.6.7 Social network analysis and systems

As SNA uses the analysis and visualisation of people’s social relations to understand the structure of their social networks, it can be applied to analyse the structure of networks in socio-technical systems, for example in the system of medicines management. At present this is a largely unexplored area. Creswick and Westbrook used the bounded network of a hospital renal ward to explore medicines information and advice interaction networks of ward staff including doctors, nurses, allied health professionals and a ward clerk.[258] The study of reciprocated interaction indicated which staff were central to how communication about medicines on the ward operated. They uncovered low levels of interaction between staff in different professional groups, with the exception of pharmacists who were central to advice-seeking networks. This was not a systems-based approach, however, it highlights the usefulness of Social Network Analysis when looking at and appraising whole systems. However, it does not take into account the complicated multi-site nature of medicines management in long-term condition management, and also the patient’s potential involvement in the optimal use of their medicines.

Salmon et al. suggested a novel use of network analysis for accident analysis and investigation.[259] They maintain that the analysis of interactions between

people in a system can offer new insight into system failures. It can also identify where communication should have happened, but failed to happen or where communication is erroneous or conflicting.

This approach can be applied to medicines management systems to explore where interactions between professionals and patients should happen, lack value, or introduce risk into the medicines management system. Whilst time and resources preclude the exploration of interactions between every actor in the system, the method enabled exploration of the system as patients experienced it – or their 'lived experience' of the system. There are several advantages to this approach:

- Patients are central parts of the system and experience the intended and unintended outcomes of the system. This research will offer a view of the system from their perspective;
- Patients are susceptible to risk in the system. This approach will enable an understanding of the relationships between actors in the medicines management network and how they impact on risk or enhance system resilience.
- Patients may act as brokers to other unknown people in the system that influence their use of medicines, for example, friends and relatives, alternative therapists, or more distant acquaintances. This approach will explore the 'hidden' people in the system who may either fill gaps through intervention or patient support, or who adversely impact upon it.

One drawback of this approach is that the understanding of the system will be limited to patients' knowledge of it, so it will overlook elements of the system that are hidden from the patient. However, it affords a view of how the patient, based on experience, perceives the system and how it does or does not work.

A whole network approach, for example through extensive documentary analysis and multi-professional and patient interviews, might have yielded this data, but this was judged to be beyond the scope of a three-year doctoral study.

3.6.8 Social support

Levels of social support have long been thought to impact on people's health outcomes;[255,260–263] and belonging to and participating in social environments has predicted disease outcomes and the onset of disease.[264,265] In particular,

research has found that lower levels of social support are associated with higher readmission and mortality rates from cardiovascular disease;[266–268] and it is now recognised that social support is a dynamic function that *"plays multiple roles in the social organization of health and illness".*[269(p125)]

Song et al. (2011) explained how social support, along with other concepts such as social cohesion, social integration and social capital, were developed from social network perspectives and are, as such, characteristics of social networks.[269] For example, social support is accessed through the network through social integration and cohesive network relationships. In this way, there is evidence that social support accessed through social networks, and especially instrumental support functions, can positively impact on adherence to medicines.[256,270]

3.6.9 Mixed methods in social network analysis

As in many branches of social and behavioural sciences there is a debate between the benefits of empirical versus more interpretive approaches and there has been an increase in the use of composite methods in recent years to bring a greater depth of understanding to networks data. Combining qualitative and quantitative approaches adds context to the data through offering a perspective on the 'lived reality' of the network.[271] It aids interpretation and appreciation of the meaning and value of relationships and offers an understanding of how networks change over time.[271] As a result, views of SNA's epistemological foundations have now been extended from structuralism to encompass more interpretive approaches such as symbolic interactionism.

Combining a qualitative and quantitative approach allows the exploration of both the structure of the network and the meaning of it.[272] Crossley argues that marrying these strands facilitates the study of social entities rather than solely structures.[273] He maintains that searching for structure without contextual factors overlooks the network actors' interconnectivity, arguing that the detached quantitative mapping of network structure creates a valuable perspective, yet it overlooks the complexity of interactions and simplifies people's 'social worlds'. The fact that we can view ties as interactional and structural increases their complexity and introduces the need to collect different types of data. This is what Coviello terms a 'bifocal' approach,[274] and one that

has been used effectively in previous doctoral work.[275] As an approach it accepts that the 'individual self' can be explained in relation to other people, which directly inherits the perspective of Mead that the 'self' arises from interactions between individuals and co-operative activities.[276]

Mixed methods studies can offer superior data quality and explanatory power to studies that use either type of method in isolation through combining qualitative and quantitative data and, importantly, strategies of analysis.[277] This study adopts a mixed methods parallel design to explore network structures and how patients interpret and experience them, thereby linking structure with the ego's perspective. It collects qualitative and quantitative data simultaneously, which necessarily limits the sample size.[277] Methods were adapted from previous successful parallel designed studies that apply methods to the same set of egos producing complementary data for methodological and practical reasons.[278] Furthermore, methods in that study analysed qualitative data thematically and also quantified qualitative data to bring additional insight and egos were sampled purposefully.

3.6.10 What does Social Network Analysis offer this research?

SNA offers a new perspective on medicines optimisation and patient safety through examining and interpreting the informal and formal structure around patients after they have left hospital. SNA also offers a systematic appraisal of the contribution of multiple healthcare professionals who operate within the system of medicines management and patients' own lay contacts to medicines optimisation. This mixed-methods approach collects quantitative data in the form of the structure of the network and value of interactions, as well as qualitative data to aid interpretation and add context to each patient's network; understanding how their interactions impact on the their medicines use.

3.6.11 Sample

Various sampling approaches can be applied to different types of network studies, and from the outset an item of concern was creating a robust sample of egos in a setting that is difficult to access and predict. For example, there is no source data available about the number of discharged patients per week and creating a random sample of patients was not possible because admissions were generally emergency admissions and the decision to discharge the patient

would usually be taken on the morning of discharge. Hanneman and Riddle suggest beginning with a selection of egos and asking the ego to report the alters to which they are connected.[279]

A quota sample was constructed (see Table 12) based on a range of variables that published literature suggest may impact on patients' use of their medicines and approaches to health and to reflect the demographics of those undergoing treatment for cardiovascular disease. The mean age of those undergoing procedures nationally in 2011 was 65, and in Site 1 and Site 2 the mean age was (63 and 64 respectively), and 74% of patients were male.[280] Socio-economic status is known to impact on health outcomes: mortality rates from cardiovascular disease are consistently higher in both men and women from lower socio-economic groups, for example mortality rates are 2.8 times higher for those in routine employment compared to those in higher managerial and professional roles.[281] The 2010 Index of Multiple Deprivation (IMD) was used to categorise the level of deprivation in the patient's home area by using their postcode.[282] The IMD is constructed through a range of deprivation indicators, for example income levels, employment, educational attainment, health outcomes and crime. A quota of 30 patients was set at each site, which was judged sufficient to draw comparisons between sites. A total sample of 60 exceeds the samples used in studies using similar social networks methods.[248,249] Selection bias was offset through matching participants to the quota as closely as possible. Patients included in the study were: those about to be discharged from hospital; those discharged back to their own homes; those discharged with at least one prescribed medicine. The principal exclusion criteria were: patients who usually live in care homes; and those who lacked the capacity to consent. Patients were approached on the ward by the researcher, given the study patient information leaflet and were given the opportunity to ask questions. This process is described in section 3.7.

Using the ego-centric framework this sample of unrelated patients was recruited on 36 randomly selected days on two hospital sites. Information about their home address, and the GP and pharmacists they used was collected to explore any overlap in the healthcare professionals (alters) they came into contact with in the weeks following their discharge. If patients had all used the same GP practice then they may have all had similar experiences because of the care

offered by overlapping HCPs. Data relating to a total of 392 network alters were collected from patients using name generator and name cueing methods.[283]

This approach yielded seventy-five egos for the study, representing a deliberate over-recruitment to compensate for predicted drop-out. Patients recruited included those whose medicines checks and discharges were observed during Study 1. Egos were self-selecting on the wards and 25 of those approached refused to take part. The main reasons for not wishing to take part were severity of illness, and time commitments. Two patients additionally expressed concerns about data security.

Table 12: Sampling matrix detailing the quota (and the achieved sample following drop-out)

Sampling Variable	Categories	Quota (achieved sample following drop-out)			
1. Location	*Site 1*	30 (30)			
	Site 2	30 (31)			
2. Patient age	*<64*				20 (31)
	>64				40 (30)
3. Patient gender	*Male*			40 (43)	
	Female			20 (18)	
4. Level of deprivation	*Low*		15 (11)		
	Medium		20 (18)		
	High		25 (32)		
Total Sample		**60 (61)**	**60 (61)**	**60 (61)**	**60 (61)**

3.6.12 Designing the data collection tools

3.6.12.1 Patient diaries

A diary method was implemented which allowed patients to keep a record of their interactions with HCPs and friends and family after they left hospital.

Diary data collection methods have several key attributes that make them a valuable way of collecting event data. Data are recorded regularly and can be organised around specific events, such as medicines contact. Diaries can be completed at the time or close to the time that events take place, and they contain information about what the person completing the diary considers important. Their main advantages are that they record events that may be hard to observe and they can also overcome problems of recall if interview or survey data is collected sometime after events occur.[284] In SNA research, diaries have

been used to record instances of communication and they are thought to collect more accurate data than questionnaires because they are a more immediate medium than a retrospective survey or interview.[285] A drawback is that they can harbour particular biases; for example under-recording of some types of encounters or events such as short meetings.[286] Effective participant briefing was designed to compensate for some of those effects.

A contact diary sheet was constructed see Appendix 2 allowing patients to record the contacts they had regarding their medicines. Recruited patients were given the option of keeping contact diary sheets for six weeks from the point of their discharge. A paper method was chosen to make the study as accessible as possible to most patients. Other methods, such as internet diaries and audio recorded diaries were considered and discounted due to the potential additional burden these methods may have placed on patients. Draft diary sheets were reviewed by a patient volunteer and by a former senior pharmacy practitioner and their feedback was incorporated in the design. Six weeks was chosen for the diary period to allow enough time for patients to have follow-up contact with their GP surgery and community pharmacist to organise repeat prescriptions. By this time any hospital discharge information should have been received by the patient's GP and transferred onto the appropriate records. Contact diary sheets were designed to document the following:

- The name of the person;
- The communication channel: telephone, face-to-face, email, letter;
- The person's professional role or relation to the patient, for example GP, nurse, pharmacist or spouse, daughter, other relative or friend;
- The outcome of the contact.

To further reduce participant burden the diaries were constructed in the form of a concise contact sheet where basic information about the contact that had occurred could be easily recorded by patients and notes made on the reverse of the sheets. Diaries were presented with easy-to-understand instructions.

In this study, contact diary sheets collected social network data about patients' medicines contacts which were used to inform the subsequent semi-structured interview as a prompt for patients to discuss the role of each of their medicines' alters. A decision was taken to make the study available to those patients who

did not feel able to complete a diary either because they felt they would not have the time or because they did not have the confidence to do so. This meant that less data was collected from a subset of patients; however those who did not feel able to keep a diary could still be included in the study. Of the sample who kept diaries (39) the ages ranged from 44-80. The mean age was 62.4 and the SD was 10.27. Eleven of those patients were 70 and older. One diary had only one entry and that patient was 61; one diary only had three entries and that patient was 80. Of those who participated but did not keep diaries (22) the ages ranged from 35-80 with a mean of 62.2 and a SD of 11.9. Seven of those patients were 70 or older. One patient kept a diary but was too ill to participate in an interview.

3.6.12.2 Patient interviews

At the end of the six-week diary period, patients took part in a qualitative semi-structured interview at a place of their choice to explore their experiences of using their medicines since discharge. Embedded within the interview was a hierarchical personal network tool which collected quantitative data about patients' medicines ego-networks following previously applied methods (see Figure 14).[249,287] This was done by showing patients a circular diagram with concentric circles which was used to position their contacts. The closer they placed them to the middle of the diagram the more valuable the patient perceived that alter to be in managing their medicines. This type of tool is a way of determining the assessment of the closeness of relationships;[288] and it was adapted for this study to assess patients' perceptions of the value of their medicines management network alters.

An interview schedule with a range of questions, probes and prompts was designed to collect relational data about their medicines management networks in additional to rich data about patients' experiences with their medicines. Different types of specific network questions were included in the interview schedule:

- Name generators: these questions aimed to identify members of patients' medicines management network.
- Name interpreters: these types of questions aid interpretation of the type of network member the alter is, for example how they are related and what type of function they perform.

- Relationship questions: these questions establish the levels and nature of contact between different alters in the networks.

The map also acted as a narration generator to encourage participants to talk about their networks and why some network members were more valued than others.

Interviews were constructed based on patients' experiences identified in the literature review to probe about the information they received about their medicines and doses, their experiences at discharge, their experiences with their medicines, and getting further medicines from their GP. During the interviews those participants who had kept contact diaries were asked to discuss their records, the people and HCPs they had contact with about their medicines, their experiences of using their medicines since their discharge from hospital, and the role and perceived value of different people and professionals they encountered in helping them safely use and optimise those medicines. They were also asked about their perceptions of how the healthcare team worked together to help them safely use and optimise their medicines and how confident they were in their medicines. Additional questions were developed so that they followed the patient pathway from discharge identified in the literature review, exploring contact with HCPs and others, and patients' attitudes towards their medicines. A patient volunteer reviewed the interview schedule and it was piloted with a different patient. All feedback was incorporated. The participants were fully briefed, the researcher established trust and rapport with the subject and steered the interview by moving flexibly through the interview schedule, focussing on what was important to answer the research questions. Semi-structured interviewing is a flexible tool that enables complex issues to be explored in depth.[215] In this context, it allowed participants to discuss aspects of their medicines they found important without constraining the interview to topics about which the researcher was already aware.

An early version of the interview schedule was piloted with three volunteers. The purpose of the pilot was to establish if terminology used in the schedule was understandable, that it did not omit areas that were important to patients and that the interview was manageable within approximately one hour. The results of the pilot indicated that the questions were appropriate; however, there

was a danger that it could produce a lengthy interview so the interviewer reduced the number of questions. Specifically questions that focussed on an imagined timeline since hospital discharged were felt to encourage a focus on non-relevant events in the patient pathway. The interview schedule is presented in Appendix 2.

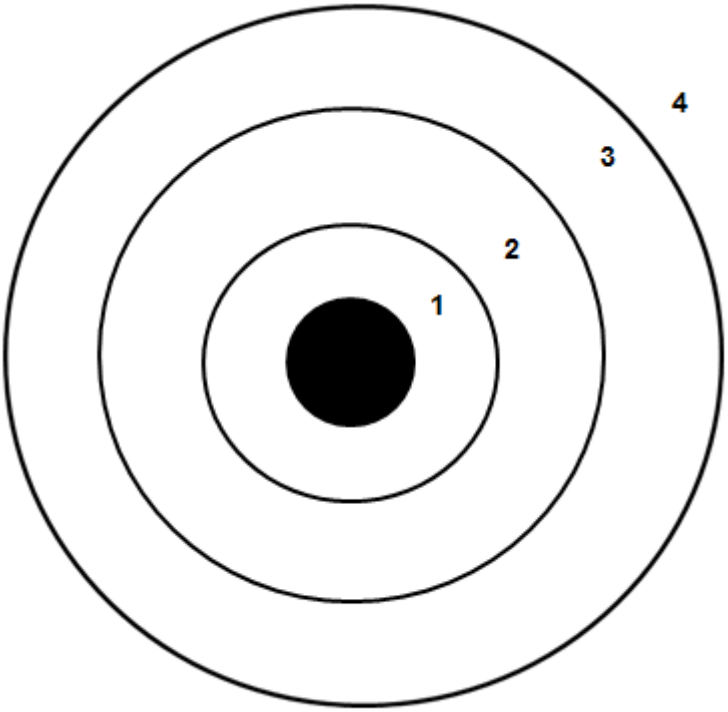


Figure 14: A hierarchical mapping tool adapted from Cheong et al.[249] Ring 1 = most valued; ring 4 = least valued.

Extracting safety incidents

During the interviews all patients were asked if anything had happened to them that had made them more or less confident in their medicines. Their answers were extracted and reviewed by two healthcare experts, who were members of the supervisory team, to establish whether a patient safety incident had occurred. A Cohen's κ was calculated to determine the agreement levels between the assessors' judgements about whether the extracted events relating to the 31 patients were patient safety incidents. There was a high level of agreement $\kappa = 0.753$ (+/- 0.108), $p < 0.0001$. The definition of a patient safety incident was taken from the former National Patient Safety Agency which has since been adopted by NHS England:

"A patient safety incident is any unintended or unexpected incident which could have or did lead to harm for one or more patients receiving NHS care."[14] This allowed the construction of a binary variable recording whether or not patients had experienced a safety incident.

3.6.12.3 Medicines experience survey

A survey was developed as a way of measuring patients' experiences of the discharge medicines management system. At the end of the interview patients were asked to complete this short 9-item questionnaire. The Medicines Experience Survey (see Appendix 2) measured experiences including: patients' self-efficacy to take their medicines; the ease with which they can access and understand information about medicines, or speak to healthcare professionals about them; and their perceptions of the services offered. Where possible, items were included or adapted from previously validated measurement tools and from other peer-reviewed sources. Based on the range of patient experiences identified in the literature, no single existing measure captured the full range of experiences considered important. For example, there are several adherence measures available, as demonstrated in the literature review in Chapter 2 and reviewed by Lavsa et al.[289] however, none captured the interactions with professionals, perceptions of a multi-professional approach, along with understanding, and self-efficacy to use medicines.

Four items about the ease of communicating and understanding medicines were adapted from the medication understanding and use self-efficacy scale.[290] This was considered appropriate as questions concerned getting information about medicines and understanding the instructions given. These adapted items are:

- It is easy for me to ask my community pharmacist questions about my medicines;
- It is easy for me to ask my GP questions about my medicines;
- It is easy for me to get all the information I need about my medicines;
- It is easy for me to understand the instructions I was given for my medicines.

Questions were adapted to account for the fact that patients may interact with GPs as well as pharmacists about their medicines. Also, the original scale referred to medicine bottles; however, patients are likely to encounter other

types of packaging.One item about perceptions of joined up care was adapted from Cheong et al:[249]

- Different healthcare professionals work together to support me in managing my medicines.

This question aimed to capture levels of agreement as to whether there is a co-ordinated inter-professional approach to medicines management.

Three items about the understanding of medicines on discharge and afterwards were adapted from the Care Transitions Measure:[291]

- When I left the hospital, I clearly understood the purpose for taking each of my medicines;
- When I left the hospital, I clearly understood how to take each of my medicines;
- I currently understand the purpose for taking each of my medicines.

During piloting it was decided that the original wording in some of the questions should be adapted in order to make the questions less complicated. For example, the question: “When I left the hospital, I clearly understood how to take each of my medications, including how much I should take and when” has been simplified so that only one phenomenon is considered and is shorter, which was considered easier for the patient to answer. The third question in this set captures any change in understanding that might have occurred in the six weeks since discharge.

The questionnaire was constructed following robust design principals to create reliable and valid measures:[292] historical events were placed in chronological order, each question asked only one thing, and respondents answered using a five-point Likert agreement scale.

3.6.13 Data collection

Interviews took place in the patient’s own home, at the hospital when they returned for a follow-up appointment, or in a different place of their choice where they felt comfortable, for example two patients were interviewed in cafes. Occasionally spouses and other family members were present during interviews. Each interview lasted approximately one hour, was audio recorded

and transcribed verbatim. Interviews took place between January and July 2014.

3.6.14 Analysing the data

Network grid

A network grid was designed to be completed by the researcher after the interview based on patients' responses about their perceptions of the contact between each of their alters. The network grid (see Appendix 2) was based on those described in another similar study.[278] It records the existence of network connections between alters in a structured way.

Grouping alter types

Alters were grouped into two main groups (personal and professional) and ten sub-groups. Professional alters were grouped into eight categories listed below:

- GPs
- Community pharmacists
- GP receptionists
- Community pharmacy staff
- Cardiac rehabilitation nurses / heart failure nurses
- Other nurses
- Hospital doctors
- Others (for example gym instructors).

Personal alters were dichotomised into groups: spouses and other friends and family.

Developing sociograms

Two different types of sociograms were produced for patients in the study. Composite sociograms were produced showing all patients at each site and their connections with their alters (first order stars). Individual sociograms were produced for each patient showing their alters and the perception of contact between those alters (first order zones). An example of a first order star and a first order zone are shone in Figures 15 and 16 respectively. An SPSS 21 database was constructed to capture the quantitative data collected during the interviews, including the number of personal and professional alters, their role and their value to patients.[293]

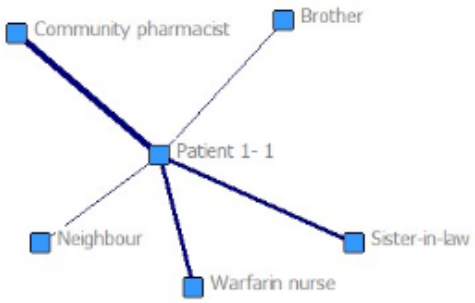


Figure 15: An example of a sociogram showing a first-order star

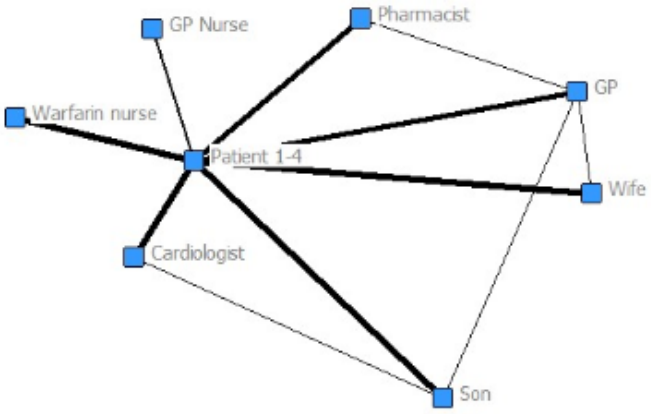


Figure 16: An example of a sociogram showing a first-order zone

Roles were classified into ten different categories. Data were captured so that each case in the data referred to an alter and ego pairing. Data were then imported into the 'ergm' software package for network data in the open-source R project for statistical computing and the composite sociograms for the first order stars at each site were graphed.[294,295]

Data from the networks grids for each patient were then entered into the Social Network Analysis UCINET 6 and graphed using the Netdraw function.[296] Using this method sociograms were drawn for the perceptions of the first order zones of each patient taking part in the study. These sociograms showed the perceptions of contact between patients' alters and are shown for all patients in Appendix 3.

Ego-network measures

UCINET 6 and SPSS 21 were used to calculate standard ego-network measures used to describe network characteristics and relate them statistically

to other variables, for example behaviours and demographics.[244] Following the methods of Hanneman & Riddle and McCarty, the following measures were calculated:[279,297]

Degree – the degree of an ego-network is the number of alters in it. This research performed separate calculations for patients' friends and family alters and their professional alters (formal and informal ties).

Diversity – a separate calculation was made for diversity in the network. This was done by assessing the number of different types of alters, for example if a patient had one cardiac rehabilitation nurse and three GPs, they would be allocated a diversity score of 2.

Number of ties – the number of connections perceived by the patient among all the actors in the ego-network, not counting the ego itself. Ego-networks were undirected so a tie between two alters was counted as two ties.

Density – the number of ties in the ego-network (not including the ego) divided by the number of possible ties. This provides a measure of how tightly connected the network is. The density calculation for an ego-network is:

$$\frac{2T}{N(N-1)}$$

Where T is the number of ties and N is the number of alters.[278] Values of 0 indicate that none of the patients' alters are connected whilst a measure of 1 indicated that all alters are connected. Traditionally density measures are viewed as measures of constraint:[243] those in denser networks are constrained by the existence of relationships between their alters. In this study it is possible that denser, more joined up networks represent more caring or safer situations for patients.

Weak components – groups in the ego-network that are connected to each other and the ego but not to others in the network. This indicates where the ego has connections that are in cohesive subgroups or different social worlds.[244] This was also calculated as the proportion of weak components in relation to the size of the network.

Brokerage – a calculation of the number of pairs of alters in the ego-networks that are not connected. This offers a measure of how many times the patient is

acting as a go-between. Normalised brokerage divides the brokerage value by the number of pairs to offer an idea of the extent to which the patient acts as a go between given the size of their network.

Betweenness – the proportion of times the patient is positioned on a direct path between others in their network. Normalised betweenness is a comparison of the values of betweenness and the size of the network. This measure is often view as one of control.[297]

These measures were analysed descriptively and student's t-tests of independent samples were used to look for differences between patients at different sites and of different genders and correlations between the measures and age were explored.

Homophily – homophily is the concept of similarity in a network based on theories that people have contact with others who are similar to themselves , sometimes summarised as *'birds of a feather flock together.*'[298] Gender homophily was calculated through generating an E-I index measure.[244] The index is calculated as follows:

$$EI = \frac{\mathrm{b} - \mathrm{a}}{b + a}$$

Where *a* is the number of similar ties and *b* is the number of different ties. It is a suitable calculation for ego-network data and as such is a superior calculation than the alternative Yule's Q calculation, which also factors in missing ties in socio-centric networks.[244]

Alter value

The value ratings given to alters by patients were compared for each category of alter. The scores were also dichotomised to give an indication of which alters were of high value to patients.

Qualitative analysis

Transcribed interview data were analysed thematically following the methods of Braun and Clarke,[299] in which text is broken down into units of meaning and grouped into themes that describe participants' views and experiences. Thematic analysis is a flexible and accessible method of analysis, developed from grounded theory. It can yield unexpected insights and is particularly suited

to translational research. Braun and Clark describe the six phases of analysis, which are detailed in Figure 17. Each of these phases was followed and NVivo 10 software was used to manage the data.[300]

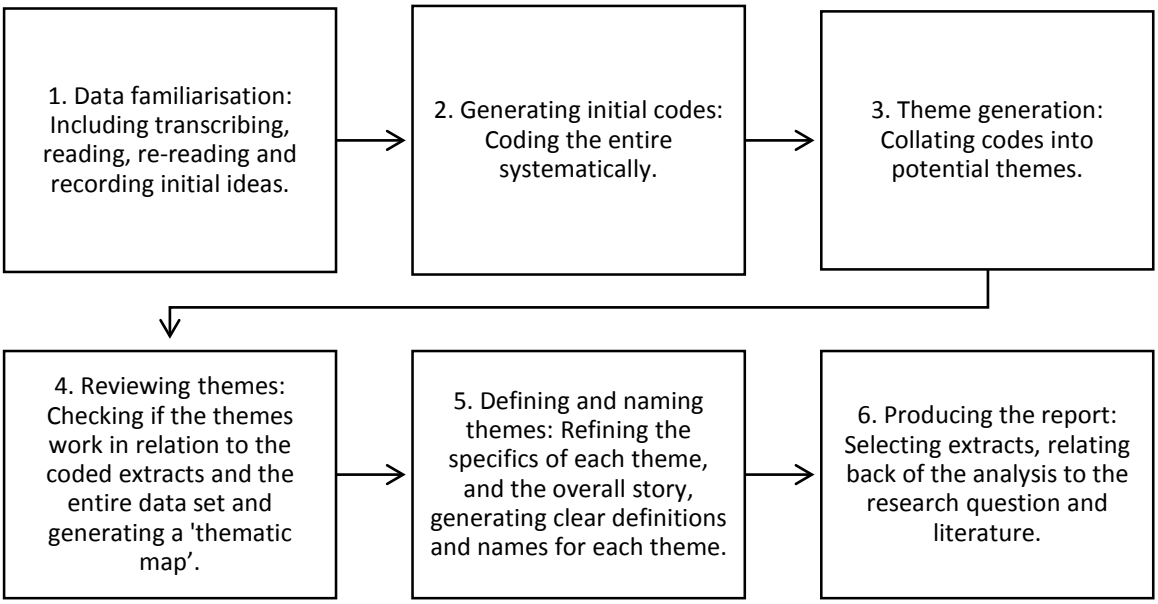


Figure 17: The stages in thematic analysis from Braun and Clarke (2006).[299]

Survey and scale analysis

Medicines experience survey data were captured into SPSS 21. Likert scale values for each questionnaire item were captured numerically: strongly disagree = 1; slightly disagree = 2; neither agree or disagree = 3; slightly agree = 4; strongly agree = 5. Frequencies and mean values for each question were calculated and inter-item comparisons were drawn and output displayed in graph format.

Item values for each patient were combined to form a scale (the Medicines Experience Scale) and a Cronbach's Alpha scale reliability analysis was performed following the methods of Field.[301] Inter-item correlations were checked to ensure that none of the scale items were highly correlated. The scale was assessed by determining its Cronbach's α scale statistic;[302] a reliability statistic of $\alpha > 0.70$ is judged to be acceptable. A further investigation into whether the scale was more reliable if any items were deleted was undertaken. A principal components analysis (PCA) – a technique that identifies linear components within a set of variables – was undertaken using a

varimax (orthogonal) rotation to ascertain if there were underlying constructs within the scale and to ascertain whether the data could be formed into subscales. There is some debate about the sample size necessary to perform a PCA.[301] Field described how views on the ratio of participants to variable range from 5-15.[301] He goes on to describe empirical research that concludes that factors with four or more loads of 0.6 are reliable. A Bartlett's test of sphericity was performed to ascertain if the inter-item correlations were large enough to conduct the analysis and a Kasier-Meyer-Olkin measure of sampling adequacy (0.72) was undertaken for each variable. The analysis was performed and components with an eigenvalue (the substantive importance of each component) in excess of 1 were extracted and compared.

Linear regression

A multiple linear regression analysis was undertaken to explore the relationship between the scale score and patients' demographic and network variables. Regression was chosen because it described relationships statistically, it estimates values of independent variables and it identifies risk factors that influence outcomes.[303] A decision was made about the appropriateness of linear regression for this data. In their guide to social network analysis Borgatti et al. described a study in which small-sample personal network data were used statistically with other data in a series of regressions, in that case measures were of depression and wellbeing.[244]

In advance of modelling the data correlations were explored between variables to negate the risk of multicollinearity and to decide which variables would be included in the models. A hierarchical blockwise approach was used to ascertain the change in squared residual values as each variable was added, to assess the effectiveness of each model in explaining the variation in medicines experience scale values and the impact of additional variables of the significance of the model**.** A decision was made not to undertake a post-hoc correction as the regression enters the variables using a stepped approach and the research is exploratory rather than confirmatory. Residuals were examined for heteroscedasticity and non-linearity. Cook's distance measures were calculated to ascertain whether individual cases had an overly large influence on the model and a case-by-case analysis of standardised DFBeta values – which calculate the differences in parameter estimates should cases be

removed – were not greater than +/- 1. The average leverage for the model was calculated and each case was explored to check that none had a leverage value greater than twice the average.

3.6.13 Limitations of the study design

Two important limitations will be discussed. First of all, this study used self-reported data which yielded insight into how patients experienced the system of medicines management, but not how the system operates from multiple viewpoints. Patient views of how healthcare systems operates have rarely been canvassed and research to understand their experiences and hear patient voices have been fragmented, and often limited to individual system outputs, such as providing patients with information about their medicines, or measures of whether or not patients actually take them. These measures are useful insofar as they offer an assessment of how well the system works, but they offer little insight into the underlying causes of risk in the system and how resilience can be enhanced. Patient views of healthcare are increasingly important in assessing the quality and safety of care, such as the friends and family test, which is essentially a net promotor score;[304] and which places individual patient perceptions of their care at the heart of the NHS quality improvement agenda. O'Hara and Isden argue that patients are the *"one common denominator across all their care experiences"* and as such have a *"unique observational position"* to identify risks in the system that may be hidden to staff.[305(p4)]

Secondly, although the use of mixed methods was an important way of understanding how the patients' networks impacted on them, it necessitated small-sample research. However, it is not uncommon for mixed methods social networks studies to use small samples, which is, indeed, a general criticism of mixed methods social network research.[277]

3.7 Ethics

This section will provide an overview of the processes followed to gain ethical approval to conduct the research and also the steps taken to ensure the research was conducted in an ethical way.

Ethical approval was sought from and granted by an NHS Research Ethics Committee (see Appendix 4); and Research and Development approval was sought and granted by two hospital trusts. A summary of the approvals is

presented in Table 13. This process took several months to complete for reasons that included:

- Differing processes in the two sites and the need to seek permission from a senior cardiology consultant in one Trust before an application could be made;
- The lengthy process of applying for a research passport. Permission to conduct research could not be granted unless the researcher had a NHS contract or a NHS research passport. The passport required that several processes were completed and documented:
  - That the sponsor organisation, in this case the University of Bradford, completes a Disclosure and Barring Services criminal records check;
  - The sponsor organisation provided evidence of an occupational health screening, including a vaccination record;
  - That the sponsor organisation verified the researcher's project and their qualifications and ability to conduct the research.
  - One Trust had a "feasibility" process that needed to be completed before a Research and Development application could be made. This took several weeks to complete.

Table 13: Ethics and research and development approvals

Approval type	References	Date granted
NHS Research Ethics Proportionate Review	REC: 13/NI/0118 IRAS: 136510	12/08/2013
Research and development approval Site 1	ReDA: 1595	28/10/2013
Research and development approval Site 2	2013/053	12/11/13

Before data collection began, informed consent was gained from participants in the study. Patients received an information sheet whilst they were in hospital and awaiting discharge detailing both the ward observations and the follow-up diaries and audio-recorded interviews. It informed them about the study and what their involvement might entail and included a consent form. The patient information sheet was designed following research ethics guidelines.[306] The researcher discussed the study with interested patients and answered any

questions. Patients were told by the researcher that they could participate in the whole study if they wished to do so, just consent to observations, or to take part diaries and/or follow-up interviews. Some patients also did not wish to participate in the diary component of the study. The researcher's contact details were provided in case patients had any questions or concerns about the research after they had left hospital. Information sheets were assessed for plain English by a member of the supervision team and piloted with a volunteer patient.

Informed consent was obtained from staff at the research sites involved in patient care. They were approached by the researcher at the beginning of the study and on each subsequent observation day. An information leaflet about the study was given to them which explained what their participation would involve and the researcher answered any questions they had about the study. They were re-assured that the subject of the study was not them as individuals, rather the system of medicines management they worked within. The briefing attempted to minimise the impact of staff awareness of the researcher observing their work on their behaviour to offset the risk of observer effects. Establishing a good relationship with staff was essential to making observations on the ward that were non-threatening so that duties were performed in their usual way, despite the presence of the researcher. The researcher asked for their written informed consent to be observed. Staff had the choice to ask the researcher to stop observing at any time if they wished; they were reassured that this would not affect their relationship with the researcher or their employer.

Data collected about individuals were anonymised through the substitution of names with case numbers that also describe the individual's role, for example CP1, for a community pharmacist. Patient names were kept separately from information collected about them and linked to stored data via a unique identifier generated by the researcher.

The level of risk to participants and researchers was judged to be low. Whilst some patients kept contact diary sheets for a six-week period we expected the number of encounters that they recorded would be low, and therefore not burdensome. Additional data collection tools in the form of questionnaires and interview schedules were purposefully designed to reduce respondent burden.

The researcher advised patients at the end of each qualitative interview to contact their pharmacist, GP or nurse if they had questions or concerns about their medicines. If the researcher had concerns that the patient was at risk because of the actions or omissions of someone in their healthcare team or because of their own actions or understanding of their medicines, then they were advised by the researcher to contact a relevant healthcare professional.

Patient interviews were usually conducted in the patient's own home. All home-based interviews took place in a main downstairs room. The researcher was also aware that the patient may recount adverse events or become upset about their health or healthcare experiences, which is classified elsewhere as the risk of psychological abuse or injury arising from the research.[223] The researcher pointed out to the patient that they could stop at any time should they wish to, for example if they were fatigued, upset or ill. Only one patient became upset about their experiences during the interview.

The researcher, who was a member of the Social Research Association (SRA), followed the SRA Safety Code of Practice which includes making sure colleagues knew the time and place of the interview.

3.8 Reliability and validity

Finally in this overview of methodology, the reliability and validity of the research will be discussed, highlighting the different steps undertaken to ensure the results of the research can be viewed with confidence.

Reliability and validity are concepts that are concerned with credibility of research.[307] They offer research audiences confidence in the results and confidence that the research tools have measured what they intended to measure. Hammersley's definition of validity suggests that research is valid if it accurately represents features of the phenomena it describes or explains.[308] Reliability is usually defined as the ability to measure a phenomenon consistently and precisely;[309] and whilst validity and reliability in research are not generally considered to be fixed concepts, rather they are firmly linked to the methods and intentions of each research project.[309] Structured observation and survey research collect primary quantitative data and as such seek to measure phenomena so that they can be described numerically or statistically.[216] Such research is often deterministic in nature in that it seeks to

identify causes of behaviour or phenomenon or to determine relationships between variables. As these types of research seek to measure phenomena objectively, there is a keen focus on the validity and reliability of the instruments used to collect the data. Many qualitative researchers reject these assessments – rooted in empirical traditions – as irrelevant to naturalistic enquiry;[310] instead trustworthiness is widely accepted as the benchmark for validity and reliability in qualitative research.[311]

The research described in this chapter employed mixed qualitative and quantitative measures and used different ways of evaluating the credibility of the methods used. This section sets out how the methods maximised the reliability, validity and trustworthiness of the research.

3.8.1 Reliability and validity in the quantitative components

In quantitative research, the data collection instruments are considered externally reliable if they are capable of producing data in a consistent way in different settings or by different researchers. This research used an observation schedule and a survey to collect quantitative data. Observation data may offer additional reliability and less biased data because they are collected as events happened rather than in retrospect; it could be argued that the more objective researcher generates the data, rather than a more 'subjective' participant. Thus observation narrows the gap between actual and recorded behaviour. During the observation stages of this research, data were collected by the same researcher using the same tool at both the study sites. As it was researcher-completed, in practice it was completed by an objective observer and completed in the same way each time it was used.

Survey scale reliability can be assessed using statistical methods. The internal reliability of the medicines experience survey question set used in this research was assessed using a Cronbach's alpha measure, which assesses the extent to which items in a multi-item set measure the same concept.[312] The survey was administered in the same way to patients at both sites.

Validity in quantitative research assesses whether the data actually record the phenomena or behaviours under investigation.[313] Validity is assessed through three routes: Criterion validity; content validity; and construct validity.

Criterion validity

Criterion validity describes how able the research instruments are to sensitively distinguish between respondents belonging to different groups.[314] As no existing observation schedule could be found to record the content of patients' hospital discharge with medicines, categories were decided through examination of previous research and policy about what patients want or need to know about their medicines. This is described in section 3.5.5. The schedule was reviewed by a patient representative and a supervisory team of healthcare experts.
The question set used in the medicines experience survey was developed based on a number of different measures, as described earlier in this chapter, and a thorough review of the literature about what patients have experienced. The question set was reviewed by a patient representative and a supervisory team of healthcare experts. It was also piloted with a volunteer patient in advance of its use in the field.

Content validity

Content validity is the extent to which an instrument captures or measures a whole concept, for example happiness. The observation schedule and the medicines experience survey were reviewed by three expert clinicians to judge if they collected the data they intended to collect. This ensured the face validity of the tools. In addition they were reviewed by a patient volunteer prior to their use who did not suggest any changes.

Construct validity

Construct validity is the extent to which the concepts in the research have been successfully operationalised. In designing the survey, instruments were constructed through triangulating patient accounts made about discharge medicines management in other research with the real-life more immediate problems described by the patient representative. The research has been informed by human factors and care was taken to embed human factors theory into the analysis of collected data through applying systems frameworks.

3.8.2 Reliability and validity in qualitative research

Golafshani emphasises that reliability in qualitative research is assessed through how trustworthy and credible it is.[310] In this research qualitative data comprised field notes made about discharge from hospital, patient diaries and

semi-structured interviews with patients. The interview schedule was constructed based on literature review, guidance from a patient representative and on feedback from three patients with whom an early version of the interview schedule was piloted. Themes identified in the data were reviewed, discussed and modified by the supervision team. As the main researcher was not a clinician, this meant that the patient experiences reported during interviews could be viewed from a lay perspective rather than through a professional lens with *a priori* professional assumptions about the delivery of care or ideal patient pathways. That notwithstanding, the researcher was aware that personal perspectives and concerns about the quality and safety of care could influence how the research was designed and conducted.[315]

Maxwell developed five general categories for judging the validity of qualitative research, which are discussed below in the context of the qualitative components of this research:[316]

Descriptive validity

Descriptive validity refers to how accurately the data record what participants experienced. After each discharge observation the researcher made detailed field notes about what had happened. During semi-structured interviews patients' accounts of their treatment were audio recorded and transcribed verbatim so the researcher did not need to rely on notes or memory to keep accurate records of what had been described.

Interpretive validity

Interpretive validity is an assessment of how well the researcher reports participants' meaning in the study. During the observation stage the interpretation mainly lay in the researcher's ability to record the meaning of non-verbal cues in relation to how staff discharged patients for example assessing whether participants appeared frustrated or distressed. If phenomena such as this occurred, the researcher made notes explaining what had been seen. During semi-structured interviews the researcher followed good practice and checked how patients' different potential meanings were understood during interviews. This minimised the risks of misinterpretation.

Theoretical validity

Theoretical validity assesses how well the researcher uses or develops concepts or theories based on data. During the analysis of observation data a previously defined framework of contributory factors was used in order to develop evidence about the contributory factors to risk during patient discharge. During analysis of semi-structured interviews, concepts developed to describe the function of patients' medicines management networks were reviewed and discussed in detail to ensure their validity.

Generalisability validity

Generalisability in qualitative research often relates to the ability of the data to describe a phenomenon for a particular group. A range of staff were observed in three settings across two sites. Observations were performed on random days and discharges were observed with different types of patients, for example those of different ages, ethnicities, genders and conditions.

Sampling for the second phase of the research was based on a quota to ensure patients with a range of demographic variables were included.

Evaluative validity

Evaluative validity assesses how well the researcher's conclusions are grounded in the data. During the observation research, field notes were made *in situ* by the researcher and used as the basis for the thematic analysis. Analysis and inferences were drawn directly from the field notes and quotations from field notes were used to provide evidence of the conclusions drawn. Conclusions drawn from the semi-structured interview data were data-driven and quotations from field notes were also used as evidence. Discussion within the supervisory team focussed on how inferences drawn were data-driven.

Triangulation

Due to the sequential embedded nature of the research design it was possible to verify the researcher's observations and analysis in Chapter 4 with patients' retrospective accounts of their discharge from hospital made during semi-structured interviews and questionnaire responses reported in Chapters 6–7. This is a form of methodological triangulation, which is a further means of enhancing the validity of this research.[221]

Overall quality assurance

The following steps were taken to ensure the overall quality of the research:

- Regular research supervision meetings enabled discussion of all stages of the research from discussion about the sites chosen, the patient health condition and the data collection tools to the themes developed and the inferences drawn. The researcher was also able to regularly and objectively reflect on the data collected with the team.
- The research was informed by the views of a patient representative who advised about the issues faced by patients when leaving hospital with medicines, the quality and suitability of the data collection tools and the suitability of patient information about the research.
- At the beginning of the project, advice was sought from the Mitchell Centre for Social Network Analysis at the University of Manchester about the research design and again later about social network data analysis.
- Conference presentations about the work encouraged peer review of the research and its findings.

3.9 Summary

This chapter has detailed the methodology and methods used in this research. Many different data collection tools were developed and applied, including an observation schedule, a semi-structured interview schedule and a medicines experience survey. The analysis methods used included descriptive statistics, social network analysis, inductive thematic analysis, a principal components analysis and linear regression.

Chapters 4–7 will describe the results of the research: firstly, Chapter 4 will present the results of the observations made of staff discharging patients on two cardiology wards; and secondly, Chapters 5–7 will present the social network analysis of post-discharge medicines management from the patient's perspective.

Chapter 4 – How are patients discharged with medicines from hospital?

4.1 Introduction

The aim of this study was to explore how medicines are managed at hospital discharge by the hospital care team. This was to understand more about what patients are told about their medicines and how staff develop patients' capabilities to use their medicines once they return home. It is presented in two parts: a quantitative analysis of the information staff offer to patients when they discharge them; and a structured deductive qualitative analysis of the field notes taken during the observations using the YCFF.[30]

The study comprised 100 observations of hospital staff and cardiology patient interactions on the day the patient was discharged from two hospital sites. Observations were of 55 patient hospital discharges conducted by nurses with the patient's medicines present. During these discussions patients would be told what medicines they were leaving the hospital with. The researcher also observed 19 pre-discharge checks of medicines where a nurse, a pharmacist or a pharmacy technician would approach the patient and explain that they were organising their discharge medicines and check which medicines were in the patient's locker. Observations were also made of 23 instances of a ward pharmacist discussing patients' medicines with them with the medicines present and three pre-discharge warfarin counselling sessions conducted by ward pharmacists. Observations took place on 36 randomly selected days between November 2013 and May 2014. The total number of observations and the type of observations made at each site is shown in Table 14.

Table 14: Numbers of observations made by type and site

Observation type	Site 1 ward	Site 1 discharge lounge	Site 2 Ward	Total
Discharge discussion	12	19	24	55
Pre-discharge check	5	0	14	19
Pre-discharge discussion	1	0	22	23
Pre-discharge warfarin counselling	1	0	2	3
Total	**19**	**19**	**62**	**100**

At Site 1 a total of 17 nurses and two pharmacists were observed, either on the cardiology ward or in a hospital-wide discharge lounge where patients were sent from the ward to wait for their medicines. At Site 2 a total of two pharmacists, one pharmacy technician, one pre-registration pharmacist, 10 nurses and one student nurse were observed, and all patients were discharged from the ward. The presence of a discharge lounge fulfilling the function of supplying patients with their to-take-out (TTO) medicines was the main difference between the two hospital sites. In this chapter the discharge lounge is treated as a separate entity. In the three places discharges were conducted, the following numbers were observed: Site 1 ward (12 patients); Site 1 discharge lounge (18 patients); Site 2 ward (18 patients).

Discharges were exclusively conducted by nurses, whilst pre-discharge medicines discussions were undertaken by nurses and pharmacists. The slightly different processes noted during data collection are shown in Figures 18 and 19, which map the discharge stages as they were observed at Site 1 and Site 2 respectively.

National policy about how patients are discharged with medicines gives little detail about what patients should be told about their medicines at hospital discharge.[72,91] The focus of these policies is to set out the inter-organisational responsibilities involved in patient transfer. Local policies are similarly vague about how patients are told about their discharge medicines.

At Site 1 policy states that patients should know how, when and what medicines they should take after discharge; at Site 2 staff guidance simply states that the patient should be given information related to their discharge medicines.

This study, therefore aimed to establish what patients are told at discharge about their medicines at these sites. The results are described in the following sections.

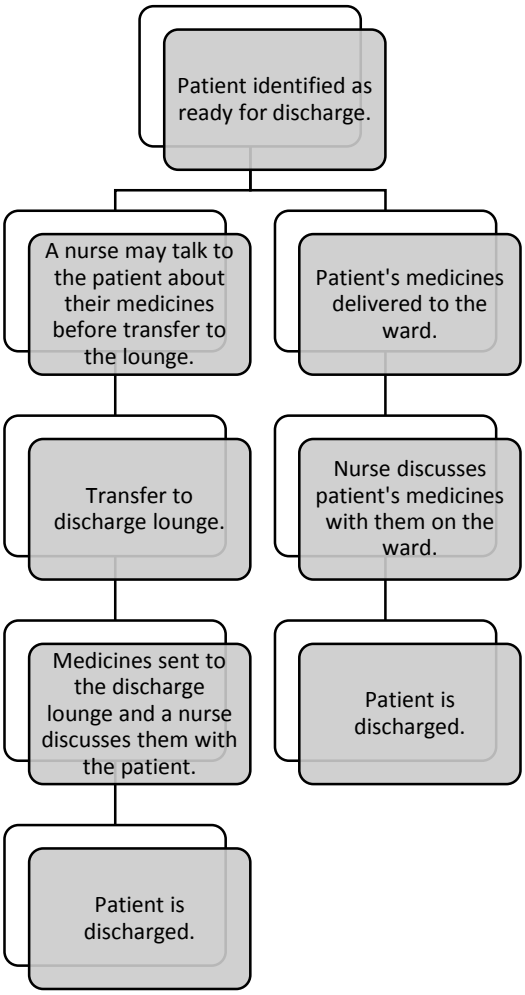


Figure 18: Site 1 discharge process

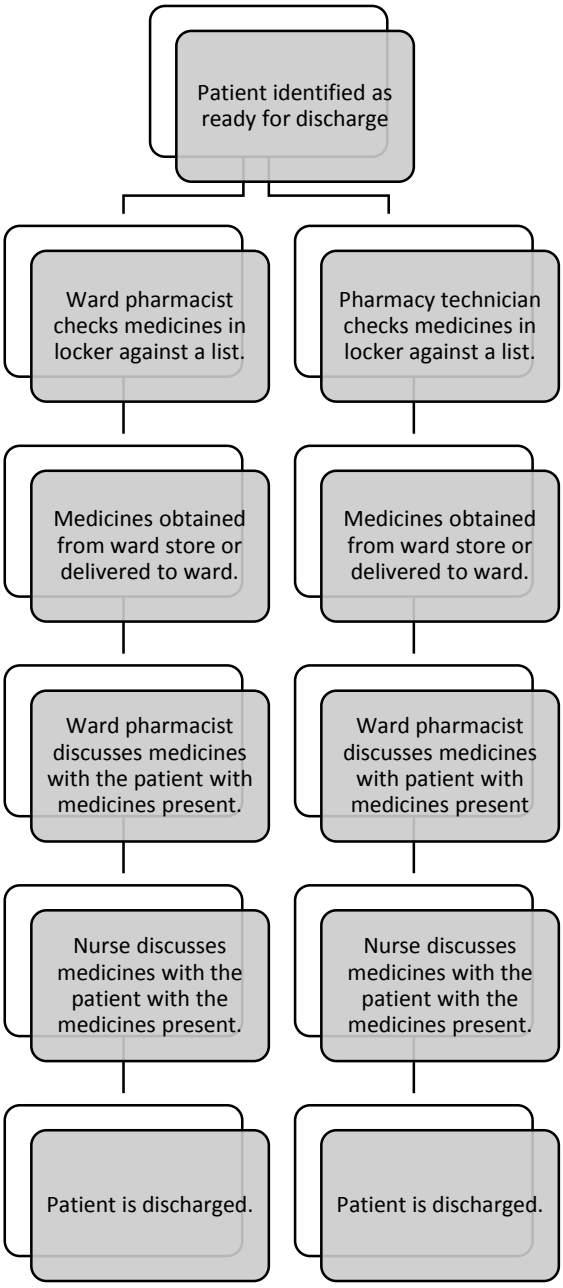


Figure 19: Site 2 discharge process

4.2 What do nurses tell patients about their discharge medicines when they are discharging them?

This section of the results explores how nursing staff told patients about their discharge medicines at the point when they were being discharged with their to-take-out (TTO) medicines. It is presented in the following sections: time spent face-to-face with patients at discharge; what are patients told about their cardiology medicines; and additional information given to patients.

4.2.1 Time spent face-to-face with patients when they are being discharged

Face-to-face interactions at the point of discharge were recorded through noting the time that the discharge started and the time it ended using a watch or a discharge lounge clock. Interactions between nurses and patients lasted between 1–24 minutes (mean=7.2; median = 5) (see Table 15); and nurses talked to patients about between 1–16 (mean = 6.7; median = 7) medicines on each occasion.

Mean times spent face-to-face discharging patients were similar at the wards at Site 1 and Site 2; however the mean time spent face-to-face with patients explaining medicines in the discharge lounge at Site 1 was much lower.

Discharges conducted in the discharge lounge at Site 1 took less time on average than those conducted on the wards at both sites. A non-parametric Kruskal–Wallis test of the distribution of independent samples indicated that the distribution of time was significantly different across the three places patients were discharged from ($p<0.05$), and the median ($p<0.01$) of the time taken to tell patients about their medicines at the discharge lounge was lower than on either ward. There was a weak association between the number of medicines discussed and the time the discharge took ($r=0.32$).

Table 15: Central measures of time taken face-to-face with patients and the number of medicines discussed.

Discharge location	Number of observations	Mean time in face-to-face discharge with medicines (SD)	Median time in face-to-face discharge with medicines	Mean number of medicines (SD)
Site 1 Ward	12	8.85 (3.98)	9.5	5.92 (3.55)
Site 2 Ward	24	8.75 (6.82)	7.5	6.88 (4.14)
Site 1 Discharge lounge	19	4.23 (3.93)	2	6.89 (3.67)
Total	**55**	**7.21 (5.74)**	**5**	**6.67 (3.81)**

4.2.2 What were patients told about their cardiology medicines?

Discharges were observed for 48 patients that included specific reference to one or more of six commonly prescribed cardiology medicines. These were aspirin, beta-blockers, statins, ACE-inhibitors/angiotensin receptor blockers, anti-platelets and glyceryl trinitrate (GTN) sprays.

The number of instances where each medicine was given to patients and discussed at discharge is shown in Figure 20. Beta-blockers were the most commonly given medicine (36 instances) followed by statins (33). ACE-inhibitors /angiotensin receptor blockers were the least commonly given medicines (22).

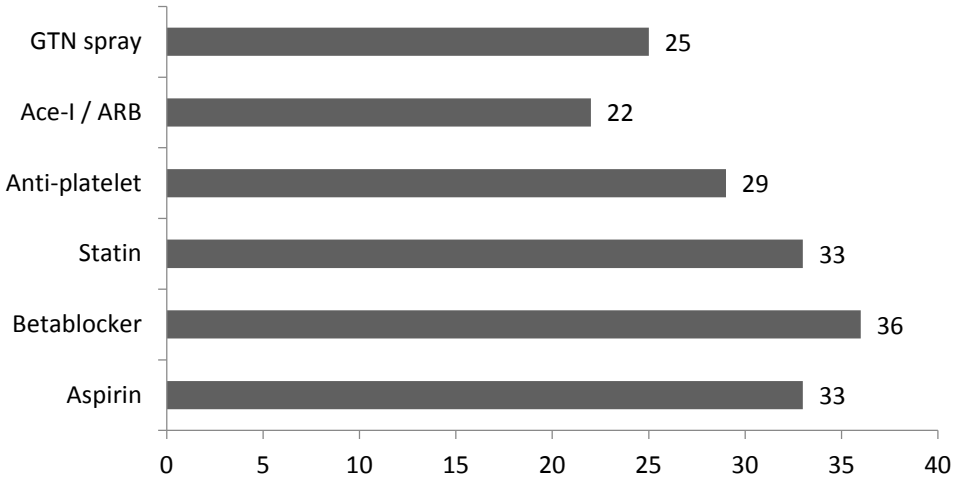


Figure 20: The frequency of each cardiology medicine given at discharge. Base = 178.

The researcher recorded the content of each patient's discharge and recorded the frequency of specific items of information to the patient. Those items were:

- The purpose of the medicine: information to help patients understand why they are taking each medicine.
- The prescribed dose: to help patients understand the amount of each medicine they should take.
- The frequency and time the medicine should be taken: so that patients understand the structure of their medicines regimen.
- How to take the medicine: this is important for certain medicines which need to be taken in a specific way. Some medicines, such as some aspirins, are soluble whilst others, such as a GTN spray, are taken in stages with specified time gaps between each stage.
- Side effects of the medicines: specific side effects of the medicines included in the study were muscle cramps (statins), fatigue and coldness (beta-blockers); headaches and dizziness (GTN spray).
- Tests: periodic tests are recommended for patients taking some medicines as part of safety monitoring, for example blood tests are often required for patients taking ACE inhibitors to monitor kidney function.

The researcher noted if the nursing staff member checked whether the patient understood the instructions for each medicine and whether patients asked any questions about any of their medicines.

The frequency with which nursing staff discussed specific items is shown in Figure 21 by medicines type and Figure 22 by site. Overall, nursing staff most commonly told patients about the timing of their medicines (127 medicines, 71.3%) and the dose of their medicines (124 medicines, 69.7%). They were told the purpose of their medicines on less than half the observed occasions (85 medicines, 47.8%) and the frequency with which they should take them on just over two fifths of the observed occasions (75 medicines, 42.1%). Nursing staff rarely told patients how to take medicines, although only certain medicines required special instructions (28 medicines, 15.7%) and about side effects on very few occasions (14 medicines, 7.8%). Tests necessary for medicines were rarely mentioned (6 medicines, 3.4%). Nursing staff occasionally checked that patients understood what they were told (23 medicines, 12.9%), and patients

asked questions about individual medicines for just over a tenth of the observed occasions (19 medicines, 10.7%). Nursing staff explained how to take GTN sprays more often than any other medicine (20 times, 80%), which is a positive result as there are complicated instructions for the use of GTN sprays that involve staged use of the spray device with time gaps between each use. Nurses explained the purpose of Aspirin less frequently than any other medicine (8 times out of a possible 33). Nursing staff in the discharge lounge at Site 1 told patients less often about most aspects of their medicines apart from the frequency of their medicines (37 times, 49.3%).

A series of chi square tests explored the association between the different medicines given to patients and the information they were given about them. The tests are described in full in Appendix 5. Overall, there was a significant association between medicines type and whether nursing staff told patients how to take their medicines ($X^2(5)= 98.885$, $p<0001$): they were told this more frequently for their GTN spray, which is to be expected due to its complicated administration. Significant associations were also identified between the type of medicines and the dose ($X^2(5) =16.891$, $p<005$) (in this case for beta-blockers) as well as the timing (for example as required, or at night) (GTN spray (X^2 (5) = 14.336, $p<0.05$). Staff also checked patients' understanding of their GTN spray more frequently than for other medicines (X^2 (5) = 20.033, $p<0.05$).

4.2.3 What were patients told about their medicines at discharge at different sites?

Tables 17, 18 and 19 show the frequency (%) of the categories of information nurses gave patients about their discharge medicines by site and by medicines category. A further series of chi-square tests explored the association between what patients were told about their medicines and the place from which they were discharged. The results of these tests are presented in Appendix 5. Overall, significant associations were found between where the discharge took place and what nursing staff told patients. Nurses on the wards at both sites told patients more frequently about the purpose of their medicines than nurses in the discharge lounge (X^2 (2) = 42.185, $p<0.001$). Nurses on the ward at Site 1 explained how to take medicines more frequently than at other sites (X^2 (2) = 8.317, $p<0.05$); and nurses on the ward and nurses in the discharge lounge at Site 1 told patients when to take their medicines more frequently than nurses at

Site 2 (X^2 (2) = 7.870, p<0.05). Side effects were explained more frequently on the ward at Site 1(X^2 (2) = 20.003, p<0.001); and nurses checked patients' understanding more frequently at Site 2 and less frequently in the discharge lounge at Site 1 (X^2 (5) = 12.798, p<0.005).

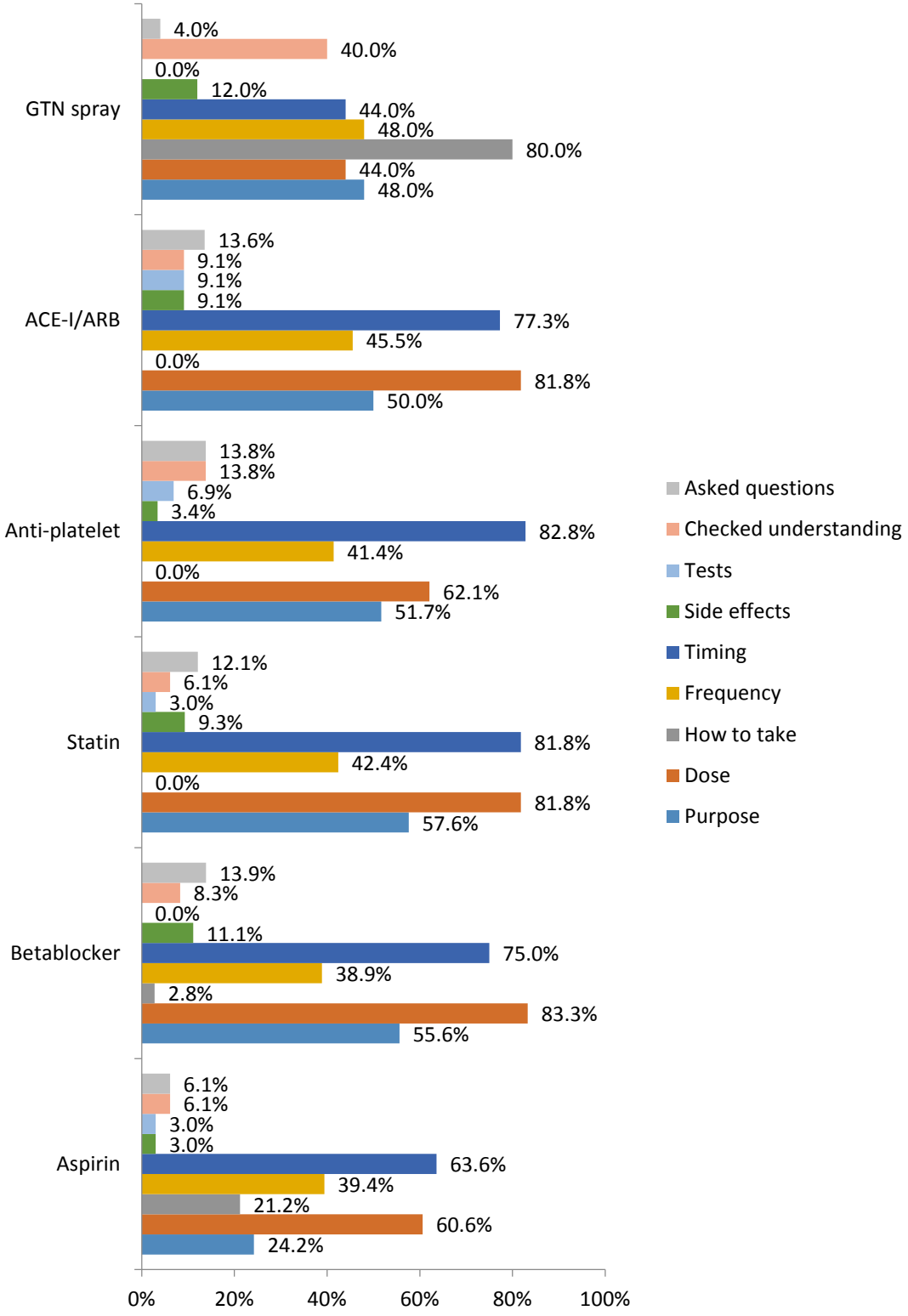


Figure 21: The frequency of staff informing patients about medicines by medicines type. Base=178 medicines.

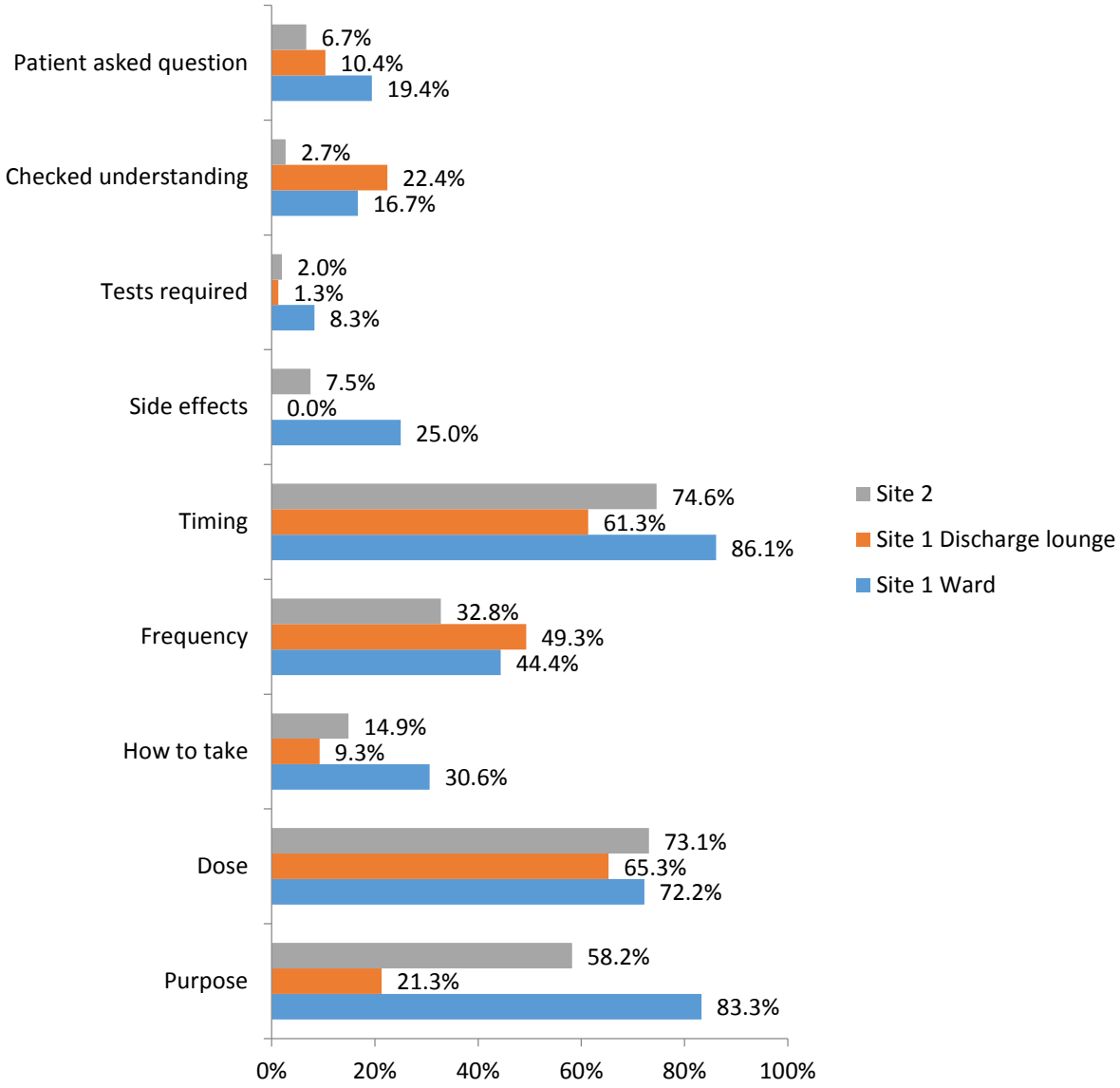


Figure 22: The frequency of staff informing patients about different aspects of their medicines. Base=178.

4.2.4 Additional information given to patients

The researcher noted during all patient discharge observations (n=55) whether nurses highlighted the written information about their medicines they could take home, whether they were told about how they should obtain repeat medicines, and whether they were told how the hospital would communicate with the primary care team. These are important pieces of information for patients to know to support their ongoing use of medicines once they have left the hospital. The results of those observations are presented in Table 16. Staff highlighted written information to take home and information about how the hospital would communicate with their primary care team to half of the patients discharged from the ward at Site 1. The proportion of staff giving these types of information

was higher (75%) on the ward at Site 2. In the discharge lounge at Site 1 just over two fifths (42.1%) of staff highlighted written information and just over a quarter (26.3%) explained how the hospital would communicate with the patients primary care team.

Table 16: The frequency with which additional information was given to patients by site

	Site 1 Ward (base 12)	Site 1 Discharge Lounge (base 19)	Site 2 Ward (base 24	Total (base 55)
Getting repeat medicines	0	1 (5.3%)	7 (29.2%)	8 (14.5%)
Highlighting written information	6 (50%)	8 (42.1%)	18 (75%)	32 (58.2%)
Hospital communication with primary care	6 (50%)	5 (26.3%)	18 (75%)	29 (52.7%)

Chi square tests indicated a significant association between where the discharge took place and whether patients were told how to get repeat medicines (X^2 (2) = 6.337, p<0.05). Nurses on the ward at Site 2 gave this information more frequently. A significant association was also detected between where the discharge took place and whether nurses explained how the hospital would communicate with their primary care team. Nurses gave this information more frequently on the ward at Site 2 and less frequently in the discharge lounge at Site 1(X^2 (2) = 10.130, p<0.01).

4.2.4 Summary of findings

- The time taken to discuss medicines at discharge with patients varied. Staff in the discharge lounge took less time discussing patients' medicines with them. These nurses had not been involved in the care of patients before they arrived in the discharge lounge.
- Nurses told patients more often about the timing and dose of their medicines than about other aspects. Timing would involve giving an indication of whether it is in the morning and at other times of day or as needed. Frequency, for example, was once per week or once per day. Often timing of doses is important to get optimal benefit from some medicines. Dose would involve the number of milligrams. Tests that might be needed were

mentioned infrequently to patients, which means they may not alert their GP practice to the need for tests should those tests not be arranged.

- Nursing staff rarely discussed side effects with patients, however as data presented later in this thesis will show, there are side effects associated with these medicines that may cause patients to discontinue them.
- Patients were rarely told about how to get repeat medicines. It may be assumed by staff that patients are aware of the processes involved and so do not think it is important to communicate this.
- Half of patients were not told how the hospital would communicate with the primary care team. A similar proportion were not alerted to the written information on the discharge summary to patients on just over half of all occasions. Staff on the wards did this more frequently than staff in the discharge lounge.

Table 17: Information given about medicines by staff at Site 1 Ward

Site 1 Ward	Number of patients	Purpose	Dose	How to take	Frequency	Timing	Side effects	Tests needed	Understanding check	Patient questions
Aspirin	6	1 (16.7%)	3 (50%)	5 (83.3%)	2 (33.3%)	4 (66.7%)	1 (16.7%)	0	1 (16.7%)	1 (16.7%)
Beta-blocker	8	8 (100%)	8 (100%)	1 (12.5%)	4 (50%)	7 (87.5%)	3 (37.5%)	0	0	1 (12.5%)
Statin	7	7 (100%)	6 (85.7%)	0	2 (28.36%)	7 (100%)	2 (28.6%)	0	0	2 (28.6%)
Anti-platelet	4	4 (100%)	2 (50%)	0	2 (50%)	3 (75%)	1 (25%)	2 (50%)	1 (25%)	1 (25%)
ACE-I/ARB	6	6 (100%)	6 (100%)	0	3 (50%)	6 (100%)	1 (16.7%)	1 (16.7%)	1 (16.7%)	2 (33.3%)
GTN spray	5	4 (80%)	1 (20%)	5 (100%)	3(60%)	4 (80%)	1 (20%)	0	3 (60%)	0

Table 18: Information given about medicines by staff at Site 1 Discharge Lounge

Site 1 Discharge Lounge	Number of patients	Purpose	Dose	How to take	Frequency	Timing	Side effects	Tests needed	Understanding check	Patient questions
Aspirin	14	0 (0%)	8 (57.1%)	1 (7.1%)	9 (64.3%)	9 (64.3%)	0	1 (7.1%)	0	1 (7.1%)
Beta-blocker	15	6 (40%)	10 (66.7%)	0	8 (53.3%)	10 (66.7%)	0	0	0	2 (13.3)
Statin	14	4 (28.6%)	12 (85.7%)	0	6 (42.9%)	9 (64.3%)	0	0	0	0
Anti-platelet	13	3 (23.1%)	9 (62.9%)	0	7 (53.8%)	10 (76.9%)	0	0	0	1 (7.7%)
ACE-I/ARB	9	1 (11.1%)	7 (77.8%)	0	5 (55.6%)	7 (77.8%)	0	0	0	0
GTN spray	10	2 (20%)	3 (30%)	6(60%)	2(20%)	1 (10%)	0	0	2 (20%)	1 (10%)

Table 19: Information given about medicines by staff at Site 2 Ward

Site 2 Ward	Number of patients	Purpose	Dose	How to take	Frequency	Timing	Side effects	Tests needed	Understanding check	Patient questions
Aspirin	13	7 (53.8%)	9 (69.2%)	1 (7.7%)	2 (15.4%)	8 (61.5%)	0	0	1 (7.7%)	0
Beta-blocker	13	6 (46.2%)	12 (92.3%)	0	2 (15.4)	10 (76.9%)	1 (7.7%)	0	3 (23.1%)	2 (15.4%)
Statin	12	8 (66.7%)	9 (75%)	0	6 (50%)	11 (91.7%)	1 (8.3%)	1 (8.3%)	2 (16.7%)	2 (16.7%)
Anti-platelet	12	8 (66.7%)	7 (58.3%)	0	3 (25%)	11 (91.7%)	0	0	3 (25%)	2 (16.7%)
ACE-I/ARB	7	4 (57.1%)	5 (71.4%)	0	2 (28.6%)	4 (57.1%)	1 (14.3%)	1 (14.3%)	1 (14.3%)	1 (14.3%)
GTN spray	10	2 (60%)	7 (73.1%)	9 (90%)	7 (70%)	6 (60%)	2 (20%)	0	5 (50%)	0

4.3 How safe is medicines management at the point of discharge?

The following section presents the results of the qualitative analysis of discharge observation field notes using the YCFF,[30] which is shown in section 3.5.8. During observations it was sometimes apparent that errors had been made earlier in the patient's care or were arising in the discharge process as it was being observed. The YCFF allowed categorisation of the contributory factors in these errors (or medication safety incidents) which were apparent in a number of the observation periods. Defences against these contributory factors – as they were observed and interpreted – are also described. Although the YCFF provided a helpful structure for analysis, there are several caveats.

The contributory factors in these errors were not always clear. Firstly, that the people being observed simply found the impact of an error and had no prior knowledge of how it had occurred. Secondly, that observation alone cannot make evident the cognitive processes of the people involved. It is difficult, therefore, to establish if (e.g.) a lapse occurred, and if so, why. However, where there was some evidence of the likely contributory factors, these are suggested. Where staff members offered explanations for why errors had occurred then these are reported with the understanding that the staff member's account may not be accurate, either because they did not wish to tell the patient or the researcher the real cause of the error, or because they themselves had misinterpreted the causes.

4.3.1 Active failures

Definition: Any failure in performance or behaviour (e.g. slip, lapse, mistake, violation) of the person at the 'sharp-end' (the health professional).

During observations, it was possible to identify active failures by staff involved in discharging patients with medicines and also the consequences of errors that may have happened earlier in the patient's pathway of care. At Site 2, skill-based mistakes included not checking the patient's locker for medicines before beginning a discharge. In one case, a nurse began talking to the patient about their medicines, explaining that the medicines on the list which were not in the bag of medicines must be the patient's own, which they should have at home. After a while, she realised that the missing medicines may be in the locker so

she checked, located them and continued to discharge the patient with the complete set.

Execution failures, such as slips and lapses, were also observed. For example, a ward pharmacist was able to pick up written information about the wrong patient, stored in a corridor on the ward, and begin speaking to the patient about the wrong medicines. Lapses included forgetting to give patients medicines that they needed to take home. For example, a patient left the ward without being given a GTN spray. This was noticed by a ward pharmacist who chased after the patient to hand him a GTN spray, counselling him about its use in the corridor. During some observations, staff began discharging patients without complete sets of medicines. One nurse on the ward in Site 2 started explaining the patient's discharge medicines to them using only one bag of medicines when there should have been two. She explained to the patient that the medicines bags were not labelled '1 of 2' and that this was an easy mistake for her to make and later found the second bag.

Sometimes it was hard to discriminate between lapses and violations, for example, making sure that a patient had all their TTO medicines at the point of discharge. In one case, a patient's statin seemed to be missing from the TTO medicines bag and the pack in his luggage only had three remaining tablets. The patient said that perhaps he had more at home. The nurse continued the discharge without any further mention of the statin or advice to the patient about getting further supplies should he need to once home.

In other cases, violations against established ward protocol seemed to be rather more obvious; some patients were allowed to leave the ward without waiting for their medicines – patients told staff members that they would either return themselves later or a relative would return later for the medicines. On another occasion a nurse discharged a patient without talking to them about their medicines – she explained that the pharmacist had already talked to the patient, although the same staff member was observed on other occasions talking to patients about their medicine at discharge after the pharmacist had previously done so. It remains unclear, however, as to whether the violations were erroneous (i.e. the staff concerned did not know they were breaking protocol) or not.

Defences

During observations, most staff took care to ensure patients received the correct prescribed medicines: staff members confirmed patients' names and dates of birth. All staff familiarised themselves with each patient's notes before initiating the discharge.

A ward pharmacist at Site 2 checked inside the boxes of medicines stored in patients' lockers and explained to patients that she needed to check with a doctor if she had a query about what had been prescribed. Most staff checked that all medicines were present before talking to the patient and some staff used the discharge summary as a guide for the conversation with the patient or cross checked all the medicines in a compliance aid with those listed on the discharge summary. Others ticked off each medicine on the discharge summary once they had talked to the patient about it.

"The nurse checked the patient name and address and checked the medicines against the discharge summary. The discharge summary was used as a reference by the nurse." (Field notes, Site 1, Ward 21/11/13)

"The pharmacist checked the medicines against the discharge summary and the patient records before speaking to the patients and checks any queries with the prescribing doctor. Pharmacist checks inside the boxes and checks the labels." (Field notes: Site 2, Ward, 04/02/14)

Helping patients to understand changes to their medicines may guard against errors occurring once they are home and beyond the care of the ward. Some staff would talk about medicines in groups, for example those that were taken at the same time, or those that worked together, for example clopidogrel and aspirin. At Site 2, a ward pharmacist would usually go to see patients with their medicines before their discharge was conducted by a nurse to explain the changes that had been made and occasionally why those changes were necessary.

"The [ward] pharmacist explained changes and some reasons for changes, for example that there is evidence that the new blood pressure medicine is more clinically effective after a heart attack. She also explained that the dose of statin will drop after six months." (Field notes: Site 2, Ward, 22/01/2014)

Additional practical help from staff during discharge tried to offset the risk of patients becoming confused by their medicines after discharge and experiencing active failures once home. For example, some staff wrote additional notes for patients on medicines boxes or discharge summary. Notes included the reasons for taking the medicines or the time of day they should be taken. Others would give explanations, such as how blister packs worked or asked the patient to explain it.

"[The] patient complained that he doesn't know what they are for. He says he gets confused and will forget. He gets upset. The nurse wrote down on the discharge summary what each medicine was for: 'blood-thinning'; 'blood pressure'; 'diabetes'; 'protects stomach'; 'cholesterol'; 'cramps'; 'pain'; 'angina'." (Field notes: Site 2, Ward, 04/02/14)

Staff gave advice to help patients continue to take their medicines, for example taking paracetamol for two weeks to help with the side effects (headaches) of nicorandil and advising them to see the GP if side effects continue. Other staff would only re-inforce that patients should not stop taking medicines should they perceive side effects.

4.3.2 Situational factors

4.3.2.1 Individual factors

Definition: Characteristics of the person delivering care that may contribute in some way to active failures. Examples of such factors include inexperience, stress, personality, attitudes.

Staff were observed to conduct discharges with medicines in different ways, with observed variation in the styles used and depth of content offered to patients. For example, staff offered different levels of detail to patients about their discharge medicines and some did not check at all if the patient understood what they had been told and gave very limited information about the medicines, for example not telling patients what the effects of the medicines would be or not telling patients about side effects. This may be related to the individual attitudes of staff members concerning the importance of talking to patients about their discharge medicines.

"[The] HCP didn't check understanding. Didn't solicit questions. No mention of what to expect from any of the medicines or any side effects. Patient

was on their own. Medicines [were] handed over in a bag. The yellow patient copy of the discharge was placed in the bag. The discharge summary was used as reference point during the discharge." (Field notes: Site 1, discharge lounge,19/11/13)

Medicines were sometimes handed to patients in a bag with little explanation about them, or boxes were shown to patients for just a few seconds whilst medicines names and doses were read out from the discharge summary.

There was a great deal of variety observed in the verbal communication style displayed by staff. Some appeared to talk to the patients in a friendly and caring way about their TTO medicines but gave limited detail. Conversations were often dominated by the nurse giving information to patients, sometimes showing them the medicines packaging whilst talking through the list of medicines on the discharge letter. They offered basic information about medicines purpose, dose and frequency and occasionally side effects and changes to medicines. Some solicited questions from the patient at the end of the discharge discussion. Whilst discharge discussions were brief, nurses were also observed to sometimes take time to explain to the patient how to use medicines and check the patient's understanding. Other staff members, however, were observed to quickly read through the list of medicines from the discharge summary, detailing some information such as doses and frequency of medicines and then placing the patient's copy of the letter in the bag of medicines without showing it to the patient or explaining what it was.

During discussions, medicines would often be left in the plastic bag in which they were issued so patients were not shown the medicines boxes, limiting their ability to familiarise themselves with their medicines before leaving hospital. These staff members rarely spent more than one or two minutes discussing TTO medicines with patients and did not seem to explain the medicines in a meaningful way that could help the patient use them once they were home. Patients rarely asked questions in these situations and questions were seldom sought by nursing staff. In one occasion in the discharge lounge at Site 1, a staff member commented that the patient may know more about the medicines than she herself did and struggled to pronounce the names of some of the medicines.

Defences

Most staff members told patients the name of the medicine and the dose and frequency with which their medicines should be taken. This may contribute to the patient's understanding of their medicines and therefore help them avoid administration errors once home. Some staff additionally offered information about the purpose of medicines, side effects and whether the medicine was new or changed, which may help the patient develop a deeper understanding of their medicines regimen and prevent them mistakenly taking medicines that had been discontinued. Some also checked that the patient understood each individual medicine; others asked the patient if they understood after they had listed all medicines.

Some staff members presented medicines to patients in a way that would help them organise or use them once home, and therefore guard against errors, for example by taking medicines boxes out of the bag and grouping them together into times of day they should be taken, or grouping together those that complement each other to treat a health condition. Other staff members would sit down with the patient to explain their medicines. Some appeared to explain medicines and their effects in detail, helping patients prepare for and recognise side effects. These nursing staff members observed were exclusively based on cardiology wards, rather than discharge lounges. Their conversations appeared patient-centred, thoughtful, in-depth and personalised to the patient's health condition and set of medicines. They appeared to be sharing medicines expertise with the patient in an easy-to-understand way. They took time sitting with the patient, soliciting questions, asking what other medical staff had told them about their medicines and checking the patient's understanding. Some explained medicines in easy-to-understand language using terms like *'controls and steadies the heart beat and helps the heart beat stronger and be a more effective pump'* to describe the effect of a beta-blocker; and an anti-platelet worked by *'stopping stickiness of the artery walls.'* Some of these nurses drew diagrams to explain the effects of medicines to patients; others attempted to empower the patient in their subsequent interactions with other HCPs, for example encouraging them to question their GP if the GP suggested changing doses or discontinuing the medicine. One patient was able to have a very detailed discussion about the side effects of a beta-blocker with the nurse who

discharged him. The nurse tried to help the patient worry less about the effects of the medicine and she emphasised that he should not stop taking any of his medicines if he was worried about them, rather he should see his GP if he had any questions.

4.3.2.2 Patient factors

Definition: Those features of a patient that makes caring for them more difficult and therefore more prone to error. These might include abnormal physiology, language difficulties, personal characteristics (e.g. aggressive attitude).

Patients were observed to display different levels of interest in the discharge consultation which impacted on the likelihood of them leaving hospital with a good understanding of their medicines. Some appeared disinterested and bored. Some patients had been waiting many hours to go home which caused them to express frustration and sometimes distress, which may have influenced how much attention they were able to pay to information about their medicines. Others who hadn't waited so long were often seemed just as keen to leave quickly.

Some patients appeared to struggle to keep up with what they were being told and were unable to quickly make notes during the time the discharge took place. One patient complained how he struggled with his memory and others appeared overwhelmed when their lists of medicines were read out to them.

"The patient was concerned to keep a list of medicines because he says he forgets what he's been told "five minutes later". The patient is struggling to keep up with what he is being told about his medicines and write things down at the same time." (Field notes: Site 2, Ward, 22/01/2014)

Patients occasionally became distracted during the consultation, for example one patient began making a telephone call on his mobile whilst the nurse began the process of discharging him. Other patients seemed confident in their medicines and so did not actively pay attention to what they were being told. In one case, the patient was so adamant that he needed no explanations that the HCP gave up trying to explain them to him.

Defences

Many patient-factor defences overlapped with individual-factor defences because some individual staff member's characteristics would try to offset patient factors. For example, staff would write things down for patients, such as *'Morning'* or *'Evening'* on medicines boxes to help patients organise them once they had left the hospital, on some occasions patients asked staff to do this as they explained they would be able to organise their medicines more effectively should this be written on the boxes for them. Other staff members would write phrases to summarise the medicines purpose, for example *'For heart',* or *'Thins blood'* on the discharge summary, which may help patients better understand the purpose of their medicines.

Some patients were very attentive during the discharge and attempted to take notes whilst they were being shown their medicines. Some appeared to be listening very intently and some asked detailed questions about aspects of their medicines that interested or concerned them, for example whether their GP would be informed about their new requirement, or if medicines had side effects. Other patients had family members, such as spouses and children, with them during their discharge who paid attention, or took notes.

4.3.2.3 Team factors

Definition: Any factor related to the working of different professionals within a group which they may be able to change to improve patient safety.

Team factors were rarely directly observed although sometimes nurses explained that the timing of patients' discharge relied on team members performing medicines-related tasks, such as writing discharge prescriptions or faxing requests for follow-up appointments. If this did not happen in a timely way, then the discharge would be delayed which may impact on the patient's willingness and ability to understand detailed information about their medicines

Defences

Few defences in this domain were observed, mainly because observations took place when only one staff member was talking to the patient. However, a ward pharmacist at Site 2 often took responsibility for charting the discharges occurring that day and their progress towards completion. The pharmacist would re-write the list of patients on the ward white board so it was easy to

understand and mark whether the patient's TTO prescription had been checked by the pharmacist and whether the patient was ready to be discharged with their medicines.

In addition, there was sometimes an overlap in what patients were told before discharge by different members of staff. For example, at Site 2 where a ward pharmacist was present, patients were told the name and purpose of new and changed medicines by the ward pharmacist and then often told this again, sometimes along with additional information, by the nurse who discharged them. This may have acted to re-inforce the information given and give patients the opportunity to hear the information again.

4.3.2.4 Task characteristics

Definition: Factors related to specific patient related tasks which may make individuals vulnerable to error.

The task of discharging patients with medicines required multiple professionals working to deliver the correct medicines to the correct patient and ensuring they are able to use them correctly. As such it is a complicated task and, as such, one which is potentially error-prone.

At Site 1, many patients were moved from the ward to the discharge lounge where staff had not been previously involved in their care and did not know them. This essentially represented an additional patient transfer (or step in the process) so opportunities to create risks were heightened because of this transfer and the different context of care. This made the task of discharging the patient something that occurred after the care of the ward had ended and that could be performed by non-specialist staff member. The ward would telephone the discharge lounge to say there was a patient to collect. The discharge lounge then listed the patient's name and ward number on a white board whilst a healthcare assistant (HCA) went to collect the patient and their notes. HCAs also regularly went to the pharmacy to collect the medicines. TTO prescriptions were prepared on the ward before the patient was collected and a note was made that medicines were not to be delivered to the ward, rather they were to be diverted to the discharge lounge. Staff in the discharge lounge did not know

the patients and when the lounge was busy staff would call out patients' names to locate them so that their discharge could begin.

Defences

Staff checked the patient's name and date of birth before talking to them about their medicines to guard against giving medicines to the wrong patients. Staff also checked if the patient had any allergies.

4.3.3 Local working conditions

4.3.3.1 Lines of responsibility

Definition: Existence of clear lines of responsibility clarifying accountability of staff members and delineating the job role.

At both sites the staff member discharging patients was not necessarily the staff member who had been in charge of caring for the patient that day. This happened if the charge nurse thought the discharge should happen when the usual staff member was not available. The discharge lounge at Site 1 was managed by a nursing sister and one of a number of nurses – usually the next nurse available – would undertake the discharge when patients' medicines arrived in the lounge. These staff members had not previously been involved in the patients' care.

At Site 2, the Ward pharmacist and the nursing teams reported to different departments, however, in terms of explaining medicines to the patients, the level of role co-ordination was not clear. The content of patient discharges often duplicated, rather than complemented, the content of discussions about medicines with the pharmacist – it was unclear whether this was by design or because the different roles of the ward pharmacist and the nurse were unclear.

Defences

At Site 2, the staff member conducting the discharge was normally, but not always, the nurse in charge of the room on the ward where the patient's bed was situated. At Site 1, the charge nurse or the ward manager decided if patients were to be transferred to the discharge lounge, where they would wait for their medicines to be delivered. Discharges conducted on the ward were usually the responsibility of the nurse in charge of the patient on the ward that day.

4.3.3.2 Staff workload

Definition: Level of activity and pressures on time during a shift.

Staff observed on both wards appeared extremely busy at all times and workloads appeared to influence their prioritisation of tasks, for example staff sometimes appeared too busy to spend a lot of time with their patients talking about medicines, which would limit the detail they would offer. However, it was not always clear whether the limited detail offered was due to staff attitudes (individual factors) or to staff workload. Time with patients seemed hurried if the staff member was due elsewhere, for example back in the dispensary, or if staff members were due to take breaks. Time spent with the patient often varied, for example some staff members would conduct the discharge standing by the patient's bed reading the medicines from a list, and in one case whilst the patient was also standing with a coat on waiting to leave the ward.

Discharges were observed to be delayed by lunch and performing care activities for other patients, for instance being asked to help a patient from his chair. Workloads meant that discharge could be conducted by a nurse that the patient did not know because they had not been allocated to that patient's room. Discharges were sometimes observed to happen very quickly in order to fit the task in around other duties and breaks.

"The discharge happened quickly. Only one new medicine (isosorbide mononitrate) and slightly more time was taken to discuss this one. The nurse took the leaflet out of the box to discuss the side effects of this medicine with the patient. The patient was standing up, dressed and ready to go home. The nurse was also standing up and tipped the medicines onto the bed. The nurse was about to go on a break. The patient asked for information about exercise but was given a leaflet about diet. The patient had been worried about doing exercise because he enjoys the gym and walking." (Field notes: Site 2, Ward, 7/1/14)

Once they were underway, discharges could be interrupted by staff members consulting the nurse about problems or asking for help. On more than one occasion this led to the patient's discharge being suspended whilst the nurse attended to other duties.

Defences

No defences were observed in this domain

4.3.3.3 Supervision and Leadership

Definition: The availability and quality of direct and local supervision and leadership.

Nursing line management reinforced that patients should be moved to the discharge lounge at Site 1, which was an internal transfer of care which impacted on the continuity of care that patients experienced.

Defences

At both sites, it was clear each day which team member was in charge of the ward, and activities in the discharge lounge were co-ordinated by a nursing sister.

4.3.3.4 Management of staff and staffing levels

Definition: The appropriate management and allocation of staff to ensure adequate skill mix and staffing levels for the volume of work.

The number of discharges varied from day to day, ranging from none to as many as nine. On days where comparatively large numbers of patients were discharged from wards, there were increased levels of work for staff members involved in preparing patients and their medicines for discharge, yet staffing levels did not appear to be influenced by the number of patients leaving the hospital. This may have impacted on the time available to staff to spend with each patient.

Defences

None were observed in this domain.

4.3.3.5 Equipment and supplies

Definition: Availability and functioning of equipment and supplies.

The availability of medicines appeared to influence how patients were discharged. Many patients waited a long time for their medicines, either on the ward or in a discharge lounge. In one or two cases staff counselled patients about their medicines without the medicines being present, sometimes describing colours or shapes of tablets. In another case, the medicine

prescribed (Valsartan) was not available in the hospital so the pharmacist advised the patient to obtain the medicine from an alternative source, which meant they may not have been able to obtain that medicine.

Patients were rarely given information about how to get further supplies of their medicines once they were back in primary care.

Defences

At Site 2, a ward pharmacist was able to dispense commonly prescribed TTO medicines from a supply on the ward. This meant that for some patients the waiting times for medicines before discharge was reduced, which may have meant they were less fatigued and more able to understand the information they were given.

4.3.4 Latent / organisational factors

4.3.4.1 Physical environment

Definition: Features of the physical environment that help or hinder safe practice. This refers to the layout of the unit, the fixtures and fittings and the level of noise, lighting, temperature and so on.

Staff were observed in three different environments: in two wards and in one discharge lounge and most observations took place in a semi-public domain. For example, in the discharge lounge patients were given their medicines in one of three rooms or in a corridor, usually with many other patients and relatives present. The main room in the discharge lounge had a television which was constantly switched on and a kitchen area where staff would prepare drinks for themselves and the patients. This environment lacked privacy for patients and may have inhibited their confidence to ask questions about their medicines. It was also a loud and potentially disorientating environment.

On the wards, most discharges took place at the patient's bedside and other patients (and sometimes other patients' family members) were often present. These environments made it possible for others to overhear the patient's diagnosis and the medicines they had been prescribed, which was potentially embarrassing for patients and may have inhibited them from asking questions about their medicines. One patient, for example, was concerned about the

impact of newly prescribed medicines on his libido and did ask questions about this, however, other patients may have been embarrassed to do so.

Defences

No defences were observed in this domain.

4.3.4.2 Scheduling and bed management

Definition: Adequate scheduling to manage patient throughput minimising delays and excessive workload.

At both hospital sites there appeared to be a high demand for beds, which placed pressure on staff to discharge patients, asking them to wait for their medicines in a different place, or transferring them to the discharge lounge. Patients were sometimes asked by a senior nurse to relocate to the discharge lounge at Site 1 if they had expressed their reluctance to do so to their own nurse. This pressure to free up beds may have limited the time taken with patients on the ward by specialist cardiology staff to explain medicines. Some patients at both sites refused to leave their beds until they had been given their medicines, one because he had done this before and waited a long time for his medicines.

"Patient's medicines were sent up on request from the pharmacy because the ward was under pressure to free up the bed. The patient refused to leave the bed to sit in the quiet room. He said he had done this before and waited ages for his medicines to arrive." (Field notes. Site 2, Ward, 7/1/14)

Defences

None were observed in this domain.

4.3.4.3 Training and education

Definition: Access to correct, timely and appropriate training both specific (e.g. Task related) and general (e.g. Organisation related).

Some staff in the discharge lounge at Site 1 appeared to be less knowledgeable about the medicines and some were observed to struggle to pronounce them. A lack of knowledge about cardiology medicines would clearly restrict their ability to offer an in-depth explanation about patients' medicines.

Defences

The depth and detail of training about discharging patients undertaken by staff at both sites is unknown. All staff were healthcare professionals and many of the staff appeared highly knowledgeable about the cardiology medicines when they talked to patients. Nursing and pharmacy trainees were mentored in the ward by more experienced staff. This meant that the style of discharge consultation could diffuse from experienced to non-experienced staff. Staff mentors would intervene if they perceived the trainee was not giving enough detail about the patient's medicines.

4.3.4.4 Support from central functions

Definition: Availability and adequacy of central services in support of the functioning of wards/units. This might include support from information technology and human resources, portering services, estates or clinically related services such as radiology, phlebotomy or pharmacy.

The timing of discharge appeared to be influenced by the capacity of the pharmacy to dispense medicines and for them to be delivered to the ward. Sometimes staff would not know the whereabouts of the patient's medicines because they had been placed on a delivery round. Delays appeared to impact on patients' capabilities and attitudes to discussing medicines.

Defences

The presence of a ward pharmacist on the ward at Site 2 resulted in medicines checks and queries being made and problems resolved quickly. The pharmacist was available to answer any questions patients had and whilst the pharmacist had a busy workload, it was possible to prioritise the organisation of discharge medicines. As many medicines were also dispensed on the ward, patients at Site 2 often went home after a comparatively shorter waiting time.

4.3.4.5 Policies and procedures

Definition: The existence of formal written guidance for the appropriate conduct of work tasks and processes. This can also include situations where processes are available but contradictory, incomprehensible or of otherwise poor quality.

Whilst medicines management and discharge policies stated that patients were to be given information about their medicines, they gave little detail about how

and where this should be done and what constituted a sufficient level of information. At Site1, policies stated that medicines management should be patient-centred, however, no additional detail or examples were given about how this should be achieved at discharge.

The discharge and medicines policies provided only very general guidance about what level of detail staff should offer patients. At Site 2 policy stated:

"The person concluding the discharge will ensure as a minimum that appropriate follow-up information is provided if applicable, medication if applicable is given, and information in relation to medication is given to the patient or relative/carer on discharge." (Site 2 Discharge Policy)

Policy at Site1 specified that:
"[At discharge or transfer] Patients (or their parents, carers or advocates) should be encouraged to be active partners in managing their medicines when they move, and know in plain terms why, when and what medicines they are taking."
And that:
"Communications with GPs, patients, carers and community pharmacists about discharge medication should be timely and comprehensive." (Site 2 Medicines Policy)

In addition, when medicines were missing from sets of TTO medicines there seemed to be no process to identify whether the patient had supplies at home, especially if the patients themselves were unsure, or whether they were missing from the set delivered to the ward or discharge lounge.

Defences

Both wards appeared to follow processes to discharge patients, as detailed in Section 3.5.7, albeit with observed individual variation.

4.3.5 Latent external factors

4.3.5.1 Design of equipment and supplies

Definition: The design of equipment and supplies to overcome physical and performance limitations.

The names of medicines staff discussed with patients were often long and sometimes difficult for both staff and patients to pronounce and understand. Some patients questioned terms they did not understand, such as 'ACE

inhibitor'; and it is possible that other patients did not ask questions when they did not understand their medicines.

Defences

None observed in this domain.

4.3.5.2 External policy context

Definition: National driven policies / directives that impact on the level / quality of resources available to hospitals.

It was not possible to directly observe how external policy impacted on how patients were discharged. However, current policy to involve community pharmacy in supporting patients with their medicines once they are discharged largely did not appear to routinely influence what patients were told by staff. Even ward pharmacists at Site 2 did not suggest patients attended community pharmacy for a MUR or enquire about an NMS appointment.

Defences

In two observations community pharmacy was mentioned to patients: one patient was explicitly told by a nurse that there were community pharmacy services available to help him with his medicines; and one patient was told to take a copy of his discharge summary to his community pharmacy after his wife mentioned that his medicines were on repeat prescription. This patient was newly prescribed aspirin and a beta-blocker in hospital.

4.3.6 Communication systems

Definition: Effectiveness of the processes and systems in place for the exchange and sharing of information between staff, patients, groups, departments and services. This includes both written (e.g. documentation) and verbal (e.g. handover) communication systems.

Patients were sometimes told that their GP practice would receive a copy of their discharge summary, however, none were told to ensure that their GP had received the information about their medicines and taken the appropriate action. Additionally, patients were not always made aware that they had a written list of their medicines as this was sometimes placed in their bag of medicines before it was handed to them.

Occasionally there was a contradiction in the medicines information given to patients. For example, a patient explained to the ward pharmacist that the doctor had told him to take isosorbide mononitrate differently to how the pharmacist had.

"The pharmacist explained why the patient should take it twice a day. The patient explained how he had usually taken it. The pharmacist explained the reason why it should be taken at 4pm as well as in the morning was to have a nitrate-free period at night-time to not become tolerant. The patient said he was told differently by the doctor." (Field notes, Site 2, Ward, 24/1/14)

On another occasion a patient was told to use a GTN spray differently by two different members of staff. In this case the gap in the time between administering the spray was of a different duration.

Potential errors that occurred outside the observation window but affected activity during observation were identified during discharge encounters. At Site 1, staff were sometimes observed to explain that ward staff might forget to mark on the to-take-out (TTO) prescription that the medicines were to be delivered to the discharge lounge and not to the ward. This would result in medicines being delivered to the wrong place, thereby increasing patient waiting time and sometimes their frustration. Staff on the ward were also observed explaining to patients that their medicines were being delivered to the wrong place which increased the waiting time and prompted discharge lounge staff to explain they were trying to track down medicines if patients complained. Nurses explained that medicines would be in the process of being delivered to the ward so they were in transit somewhere in the hospital and staff were not aware of the medicines' exact location.

Occasionally, not all medicines listed on discharge paperwork were delivered to ward or to the discharge lounge for the staff member to use when discharging the patient, for example some medicines were missing from bags of delivered medicines and this was noticed and communicated to patients during their discharge. There may have been a number of reasons for this, for example errors made by staff on the ward when ordering patients' medicines or errors in the dispensary when preparing and issuing them. In some cases it became

unclear during the discharge if patients had supplies of missing medicines themselves at home.

Defences

Patients were sometimes told their GP would be informed of their hospitalisation and their medicines regimen.

"The nurse explained that the discharge summary would be faxed and posted to the GP and that [the consultant] would write to the GP. Told that a copy of the discharge summary would be kept on the ward. Told to call the ward if they had concerns." (Field notes Site 1, 21/11/13)

Each patient was given a written list of medicines to take home and whilst at Site 1 this was initially a poor-quality, hard to read copy, they changed their systems so that patients received printed copies during the observation period. Before this change, one staff member pointed out to a patient that their 'yellow' copy of their discharge summary might be difficult to read and photocopied a better copy for the patient.

4.3.7 Safety culture

Definition: Organisational values, beliefs and practices surrounding the management of safety and learning from error.

Values and beliefs cannot be directly ascertained during observations, however, some cautious inferences can be drawn from these observations. Processes and individual behaviour observed at the 'sharp-end' can be indicative of the safety culture of an organisation. The two sites were observed to operate very different methods for managing medicines at discharge. Site 2 had an allocated ward pharmacist who would see each patient shortly before they were discharged to highlight which medicines were new and which had been changed or discontinued, which potentially enhanced patients' knowledge of their new medicines regimens and may prevent medicines errors once they were home. Site 1 also had an allocated ward pharmacist, who changed three times during the observation period. The pharmacist at Site 1 was less involved with the patient at discharge, even though they would have had a face-to-face interaction at some point during the patient's hospitalisation.

Site 2, like Site 1, had a discharge lounge where patients could wait for transport, however medicines were always handed to the patient on the ward, usually by a member of staff who had been involved in their care. Medicines explanations to patients were usually given more emphasis on wards compared to the discharge lounge, where giving patients' medicines seemed to be more process driven, aimed at completing the discharge rather than on the needs of the patient.

Defences

No defences were observed in this domain.

4.5 Discussion

This section has explored the various contributory factors to risk from medicines and defences that come into play when patients are discharged from hospital.

Contributory factors included:

- Active failures: execution failures, for example lapses; skill-based mistakes; and violations;
- Individual factors, such as staff attitudes to counselling patients;
- Patient factors, such as tiredness, frustration, becoming distracted and eagerness to return home;
- Team factors, such as waiting for colleagues to perform tasks;
- Task characteristics, such as the complex nature of discharging patients with medicines and internal patient transfer;
- Lines of responsibility, for example the responsibility for discharging individual patients;
- Staff workload, which may result in interruptions and limited time to conduct discharge conversations about medicines. Importantly, no defences were observed in this domain;
- Management of staffing levels, for example on some days large number of patients was discharged and staffing did not change accordingly;
- Communication systems, such as the ordering and internal delivery of medicines;
- Scheduling and bed management.

Defences included:

- Defences against active failures, such as using the discharge summary as a checklist;
- Patient factors, such as note-taking during the discharge and having relatives present;
- Individual factors, such as in-depth, person-centred conversations about medicines;
- Team factors, such as a ward pharmacist charting discharge progress;
- Equipment and supplies, such as medicines being available on the ward.
- Training and education, such as having staff who were knowledgeable about cardiology medicines (nurses and pharmacists) on the wards;
- Support from central functions, such as the presence of a ward pharmacist;
- Communication systems, such as giving patients a written list of their medicines.

It was clear that in some cases the safety of patients could be improved if the discharge took into account patients' individual capabilities, for example a patient's ability to take notes and absorb large amounts of complicated information. Discharge with medicines was also sometimes conducted with staff who had no prior involvement in the patient's care. Risk was introduced when team pressures affected the timing of discharge and the amount of time the staff member had to spend with the patient explaining their medicines. At one of the sites hospital policy had introduced an additional patient transfer to a discharge lounge to wait to be discharged. The rationale for this transfer off the ward was to free-up bed space once it had been decided that the patient was well enough to go home. It is possible that giving the patients their medicines is not seen as a core element of their care, rather it is a process that must be completed before they can go home. The ward needs to see medicines as a central patient care issue with a demonstrable knock-on effect in primary care.

Using the YCFF as a framework to exploring the safety of discharging patients with medicines presented some difficulties. First of all the tool was compiled from a systematic review which explored the contributory factors in patient safety incidents. To use the framework it was necessary to predict how

observations in some of the domains might impact on the safety of how medicines were managed by the patient, their families and healthcare professionals. For example, not encouraging patients to ensure their GP practice had been made aware of changes to their medicines may have resulted in some patients receiving prescriptions for incorrect medicines. Indeed, Chapter 6 will describe patients' accounts of receiving incorrect repeat medicines sets after leaving hospital. However, at the time observations were made, the researcher could not be aware of whether subsequent patient safety incidents occurred. In addition, incorrect sets of medicines arriving on a ward to be given to a patient would qualify as a patient safety incident, even if the staff member at the *'sharp end'* noticed and took action. However, observation at the *'sharp end'* made it extremely difficult to identify the contributory factors to such events. It was also difficult using observation alone to identify where latent organisational factors and latent external factors, such as internal and external policies, might have contributed to a potential patient safety incident. In the same way, observing and identifying safety culture is difficult and inferences needed to be made to assess how culture impacted on practice on site.

This study has explored the variation in the practice of discharging patients with medicines from hospital. Recent NICE guidance on medicines optimisation states that medicines-related communication systems should include transfer information about what the patient, their family members and carers have been told about the patient's medicines when their care is transferred between providers.[72] It offers no suggestions about what patients should be told about their medicines when their care is transferred, although it does emphasise that medicines optimisation should be patient-centred. This lack of detail in external policies is reflected in the internal policies of both hospital sites, which also do not give guidance about what patients should be told about their medicines when they are leaving the care of the hospital with their medicines in front of them and an HCP at their side. Whilst we do not know from this study what patients were told about their medicines during their stay, for some patients the point of discharge may be the first time they had been talked through their medicines as a group and in a systematic fashion. The depth of preparation patients receive to self-manage their medicines is likely to impact on their capability to safely manage them and also their confidence in them once they

have left hospital. Given that patients have reported feeling confused by their medicines after discharge and can find it difficult to co-ordinate support in primary care, additional time spent talking about sets of medicines with caregivers may help enhance their abilities with their medicines and reduce both re-admission and preventable harm. Chapter 6 will describe how confused about their medicines some patients were after leaving hospital.

Medicines information has been found to enhance understanding and reduce anxiety about side effects.[317] The number of patients being told about side effects in this study was low compared to other aspects of their medicines, such as medicines purpose. Nationally, there is a similar picture: the most recent CQC/NHS in-patient survey reported that 41% of patients who had TTO medicines were not told about medicines side effects to look out for.[318] There is debate about the impact of explaining side effects of medicines to patients; and the *'nocebo effect'* of giving patients negative expectations about their medicines has been discussed in depth.[319–321] However, explaining effects to look out for in a patient-centred way, exploring the level of detail that is right for each patient and empowering them to seek help should they wish to or need to, might contribute to the safe management of their treatment.[322] Giving structured information about levels of risk may also be an important step.[323,324]

In this study, the task of giving patients their discharge medicines occurred just before they left the ward and medicines education activities at this time concerning their medicines varied from care-giver to care-giver, and as such it was an individual factor in sub-optimal practice. Although all patients were given written information, not all staff highlighted this information to patients, which may explain why patients in another study reported not receiving written information.[144] On the ward, the staff discharge style seemed to be the individual choice of the staff member, mediated by the relationship between the staff member and the patient, and the pressures on the individual staff members. The discharge lounge appeared to be highly process-driven: its focus was on completing the process of discharging the patient by handing them their medicines and requesting their signature on the discharge summary. From the observer's perspective, it appeared to be a task that occurred after the *'caring'* duty of the hospital had ended, despite the best intentions of the staff on duty. In this way, the task characteristic became a contributory factor because it was,

in many cases, detached from other care tasks and managed discretely. The fact that patients were transferred to the discharge lounge risked their safety as it constituted an additional gap in the continuity of care;[41] and so required an additional hand-off of care to discharge lounge staff.[44]

Patient factors were evident during many observations: many patients appeared to be anxious to be discharged and perhaps did not pay full attention to the list of medicines that was read to them. They had, after all, been in hospital after experiencing a health crisis or intervention. In 2005, a multi-agency report identified that giving patients medicines just before discharge was a problem in the patient journey because it allowed no time for meaningful patient education or advice.[92] In this way, giving patients their medicines and helping them understand them is not perceived as an integral part of the care that the hospital offers. Providing more in-depth support with medicines at discharge and bridging the gap in care by continued support after discharge may have a significant impact on hospital resources and it is debatable whether the time, skills and money are available to do so.[55]

External policy for patients with cardiology conditions to access the clinical services of community pharmacy did not, in most cases, impact on what they were told at discharge. Patients were signposted to their community pharmacy for help with their medicines only twice. This suggests a continued lack of integration of community pharmacy into the discharge pathway in a role supporting medicines use. Nevertheless, community pharmacists can play a valuable medicines management role for patients after discharge.[129,325,326] Recent guidance from the RPS Innovators Forum suggests that hospital patients should be routinely referred to community pharmacy services after their discharge to support their medicines use,[327] not least because community pharmacy can help identify problems patients may have with their medicines after they have left hospital.[125–127,129,195] The role of community pharmacy after discharge is explored in more detail in Chapter 6. Patients were also told that their GP would be informed that they had been in hospital, although they were not given any additional information about what to expect (or not to expect) from their GP practice. A clearer care pathway set out to patients at discharge would help them understand more about who is responsible for their ongoing care and who they should seek support from after they arrive at home, especially if they

have co-morbidities which may increase their chances of readmission.[328,329]

Who should talk to patients about their discharge medicines?

In many instances in this study a nurse who knew the patient and had been involved in their care conducted the discharge. If the staff member knows the patient then it is likely that their understanding of that patient will impact on their ability to provide person-centred as well as safe care. For example, the patient may have previously expressed preferences or concern about medicines to staff on the ward that other staff members might not be aware of. Much has been written about the concept of 'knowing the patient'. In the 1970s patterns of knowing the patient were described by Carper,[330] encompassing professional skills; professional knowledge and personal knowledge of the patient. A later review of the literature subsequently identified several key areas of knowing the patient:[331]

- Understanding and treating the patient as an individual – which upholds a professional nursing value;
- This results in individualised care;
- It is an integral part of nursing decision making;
- That the amount of time the nurse can have with the patients affects how well they can know them, which is influenced by staffing policy;
- That it enhances outcomes and earlier recovery.

Further work drew a distinction between 'knowing' the patient through information sources such as the medical records, a personal care record used by different staff on the ward who care for the patient, and other sources of information such as verbal information from the patient and their family, and verbal information, such as hand-offs, from colleagues.[332] Staff on the wards in this study often had more time to 'know the patient' through using these sources of information than staff in the discharge lounge. They also had more specialist knowledge of cardiology conditions and knowledge of the medicines prescribed to treat them, which constitutes a higher level of specific clinical expertise. Staff in the discharge lounge had fewer resources to rely on, such as hand-off information and medical notes. Not knowing the patient is more aligned to a process led, managed model of healthcare,[333] which reflects the nature of the observations made in the discharge lounge at Site 1. Indeed, recent work in the

area of knowing the patient acknowledges the challenges posed by discontinuity of care and staff workload in acute healthcare environments which mean the process of knowing patients is not supported.[334]

This chapter has explored how patients are discharged from hospital with their medicines. It has set the scene describing how safely the hospital prepared patients as they were discharge to manage their medicines once they were back at home. Using Social Network Analysis, Chapters 5–7 will explore how patients and their medicines are subsequently managed once they have been transferred back to primary care. In the first instance the structure of the patients' medicines management networks will be described through ego-network analysis.

Chapter 5 – The structure of patients' ego-networks

5.1 Introduction

This chapter presents the results of the structural analysis of 61 patients' medicines management ego-networks. It is based on data collected in patient diaries (n=39) and augmented with semi-structured interviews (n=60) and network visualisation six weeks after hospital discharge.

The results are in the following four sections: ego network size; alter roles in patients' ego networks; ego-network connectedness; and medicines management alter value to patients. To aid interpretation of this chapter definitions of some of the commonly used terms in SNA are detailed below:

Actor	An individual (a patient or a contact of a patient)
Alter	Another individual present in the ego's network
Betweenness	A measure of the extent to which an actor connects other actors
Broker	An individual who connects other individuals to each other
Degree	The number of ties of one individual
Density	A measure of the proportion of connections in the network
Dyad	Two individuals who are connected
Ego network	The personal network of one individual (patient)
Ego	The individual (patient) who is the focus of interest
Homophily	The similarity between actors in a network
Sociogram	A visualisation of the network showing individuals and the connections between them
Ties	Connections between individuals

5.2 Patients' ego-network size

The mean age of the achieved sample of 61 patients was 62.9 (SD 10.7) and their ages ranged from 35–80. At Site 1 patients' mean age was 60.4 (SD 12.0) with an age range of 35–79; at Site 2 the sample mean age was 64.9 (SD 9.1) with an age range of 44–80. Patients reported different personal and professional alters fulfilling medicines management functions during the post-discharge period. Together, patients reported 392 medicines management

alters in networks of different sizes. Individual patients reported between 1–15 alters.

The ‘degree’ of a network is the number of ties recorded for one individual. It is possible for directed networks to measure ‘in-degree’, which is the number of inward connections present, and ‘out-degree’, which is the number of outgoing connection present. However, patients’ ego-networks in this study were undirected and so a total degree measure is appropriate. Overall, patients recorded a mean degree of 6.50 (2.72) and a median of 6. Men had a mean network degree of 6.30 (2.76) and a range of 1-15 alters whilst women had a slightly larger mean degree of 7.0 (SD 2.63) and a range of 4-14 alters. Males at Site 1 recorded a mean degree of 5.9 (SD 2.91) and a median of 5. Females at Site 1 recorded a mean degree of 6.22 (SD 2.39) and a median of 5. Males at Site 2 recorded a mean degree of 6.55 (SD 2.58) and a median of 6.5. Females at Site 2 recorded a mean of 7.67 (SD 2.87) and a median of 6.

Two-tailed independent samples t-tests indicated there was no significant difference in the degree recorded between males and females (t = -1.108 (58), p = 0.313) or between people at different hospital sites (t = -1.401 (58), p = 0.166). Using a Pearson correlation calculation, no significant correlation was found between ego network degree and patient age (r = -0.149, p = 0.251). This suggests that patients had similar numbers of network alters regardless of the hospital site they were discharged from and their age and gender. It is likely that other factors, such as their health status, for example their number of co-morbidities – may influence their network degree. A diversity score was also calculated for each patient’s ego-network through determining the number of unique alter types in their networks. This is presented in Table 20, along with the size and mean degree for patients by site and gender. There was a difference in the overall degree mean and the diversity mean of 0.96 which indicates that whilst there is duplication of professional roles in patients’ networks which may indicate a gap in continuity of care, that duplication is limited.

Table 20: Ego-network measures by size and mean degree

	All	Site 1 male	Site 2 male	Site 1 female	Site 2 female
Number of patients	61	21	22	9	9
Number of alters	392	123	134	56	79
Professional degree range	1-9	1-9	2-8	2-8	3-7
Lay degree range	0-8	0-6	0-7	0-5	0-8
Professional degree mean (SD)	4.62 (2.04)	4.38 (2.59)	4.68 (1.78)	4.45 (1.94)	5.22 (1.30)
Lay degree mean (SD)	1.80 (1.70)	1.43 (1.43)	1.86 (1.61)	1.89 (1.45)	2.44 (2.55)
Diversity range	1-12	1-12	2-9	3-7	4-9
Mean diversity	5.40 (2.00)	4.90 (2.32)	5.68 (1.93)	4.89 (1.17)	6.33 (1.80)

Each patient had contact with at least one healthcare professional or healthcare support staff member, whilst at both sites some patients reported no friends and family in their medicines management networks. There were high levels of variation in the degree of patients' ego-networks presented in composite form in Figure 23 and Figure 24, which are sets of sociograms depicting the ego networks of patients discharged from Site 1 and Site 2 respectively. They visualise the patients and their professional and personal network alters and demonstrate the variation in degree and composition within patients' ego-networks. Males at Site 1 had the widest range of alters and the widest range of networks diversity scores. Overall, patients reported more professional than personal alters in their medicines management ego-networks.

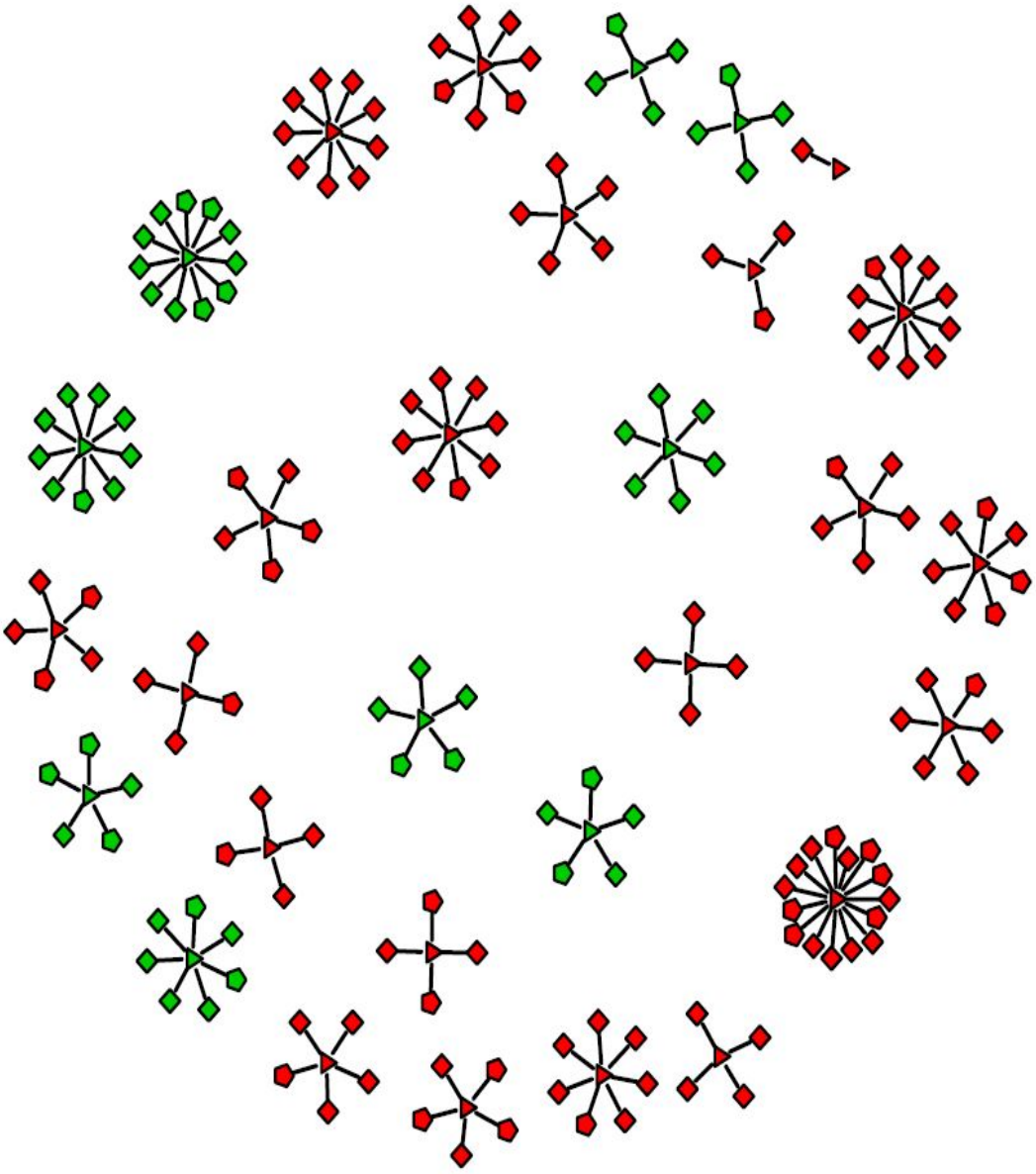
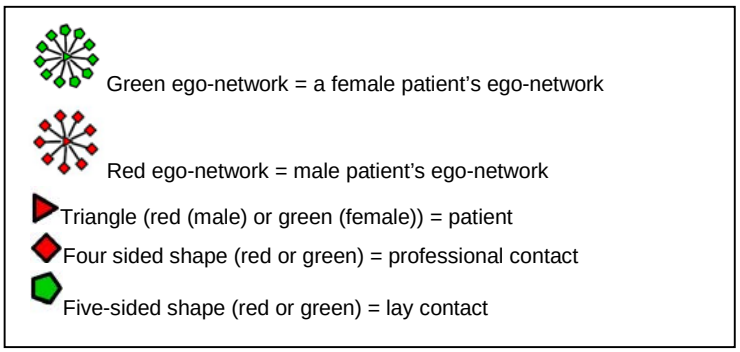


Figure 23: Composite sociogram of 30 ego-networks of patients discharged from Site 1. Triangles = patients; lines = ties; green shapes represent the networks of female patients; four-sided shapes=professional contacts; five-sided shapes = lay contacts.



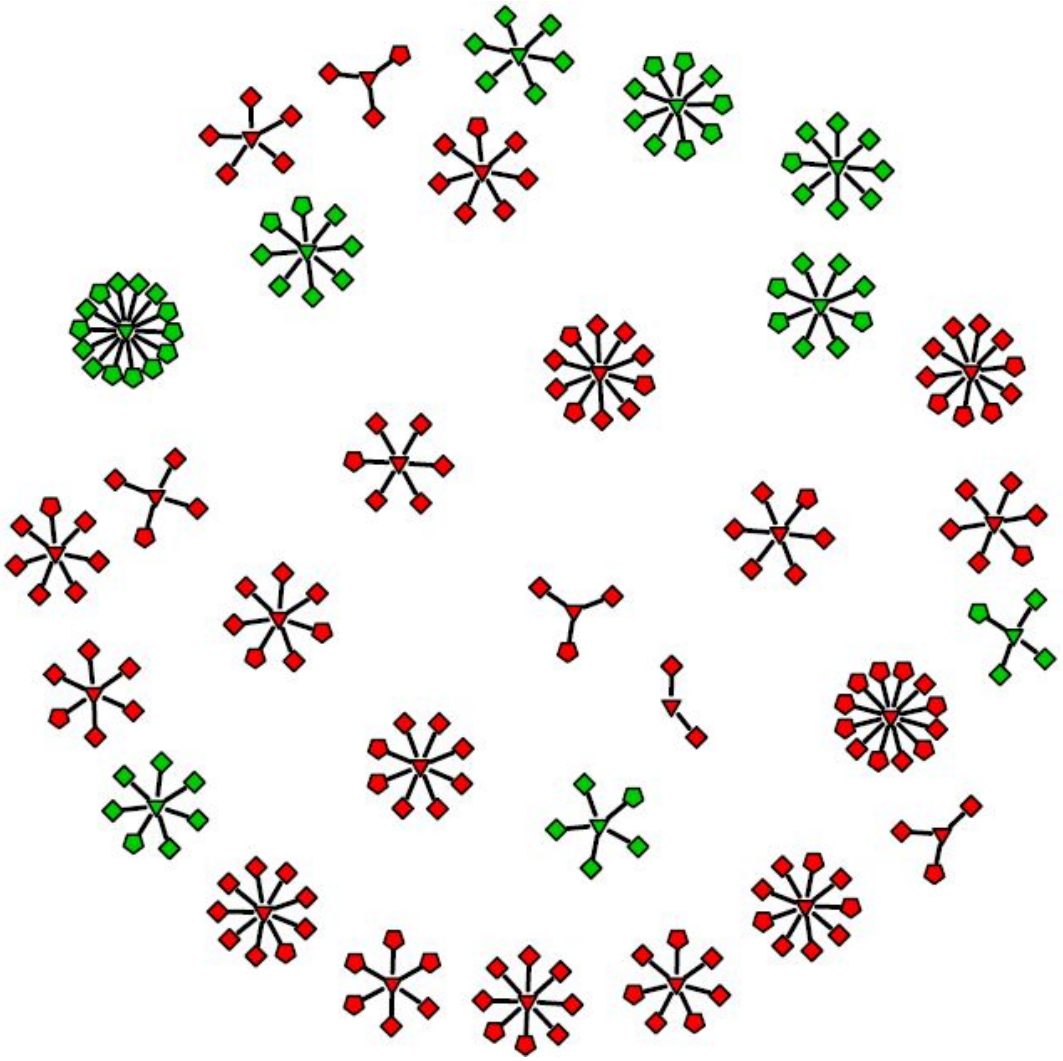


Figure 24: Composite sociogram of 31 ego-networks of patients discharged from Site 2. Triangles = patients; lines = ties; green shapes represent the networks of female patients; four-sided shapes=professional contacts; five-sided shapes = lay contacts.

5.3 Alter types in patients' ego-networks

Alters were classified into one of ten professional (8) or lay (2) groups, as described in Chapter 3. The composition of patients' ego-networks by site and gender is presented in Figure 25 and discussed in detail in sections 5.3.1 and

5.3.2. GPs made up nearly one sixth (14.5%) of patients' medicines management network alters, and 11% were community pharmacists. Specialist cardiac rehabilitation or heart failure nurses comprised nearly a tenth (9.4%) of all alters. Friends and family other than spouses were the largest single group of alters. Spouses of male patients appear more frequently in medicines management networks than the spouses of female patients. Females at Site 1 had contact with a greater proportion of GPs and a smaller proportion of community pharmacists than other patients whilst male and female patients at Site 2 reported a lower proportion of hospital doctors playing medicines management roles.

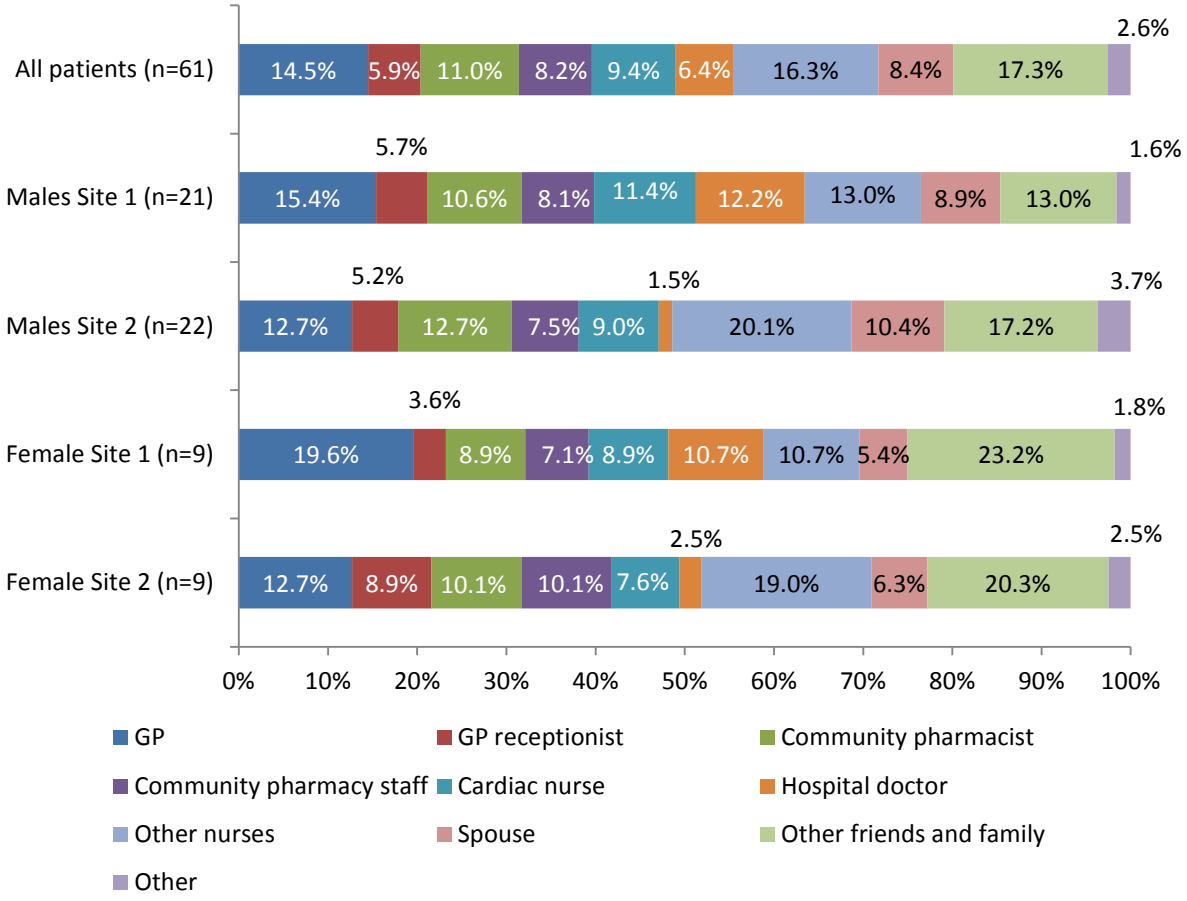


Figure 25: Ego network alter roles by site and gender.

Different personal and professional medicines management alters are explored in more detail in the following sections, initially with a description of patients' professional network alters.

5.3.1 Professional (formal) healthcare alters

Several different healthcare professions were reported by patients as being part of their medicines networks and most of these roles were clinical, including GPs, GP practice nurses, hospital nurses, and hospital doctors. Patients also had contact about their medicines with community pharmacists and community-based services, such as community nurses. Many patients had contact with specialist nurses, such as cardiac rehabilitation nurses, heart failure nurses, COPD nurses, stroke nurses and warfarin nurses. In total 61 patients had contact with 282 professional alters.

Nurses (other than specialist cardiology nurses) were the most commonly reported professional alter type. Over half the sample (36) had contact with a total of 64 nurses involved in medicines management. These nurses were GP practice-based, clinic-based, but also hospital-based. GPs were the next most commonly reported HCP network member type: 45 patients recorded direct contact with a total of 57 GPs, indicating that a quarter of the sample had no direct contact with a GP in the six weeks after they left hospital. Community pharmacy was the next most common category of professional alter: again, just over half (36) of patients recorded contact with 43 community pharmacists. Cardiac rehabilitation nurses, categorised separately to other nurses, were present in the networks of 28 patients who had contact with 37 cardiac rehabilitation and heart failure nurses concerning their medicines.

Some patients reported contact with multiple HCPs in the same profession, for example they spoke to or saw more than one GP whilst others interacted about their medicines with more than one community pharmacist, as indicated in the individual sociograms in Figure 26 and Figure 27 visualising the network of Patient 1.33, who had contact with four GPs about medicines during the data collection period, and Patient 2.21 who had contact with two community pharmacists.

Other patients recalled no direct contact relating to their medicines with primary care providers, such as community pharmacists and GPs, in the period following their discharge from hospital. In some cases patients used proxy contacts, such as a GP receptionist who would relay messages, or pharmacy counter assistants. Although the majority of patients had contact with a GP,

many patients described their difficulties accessing a GP, even though they thought they would benefit from an appointment.

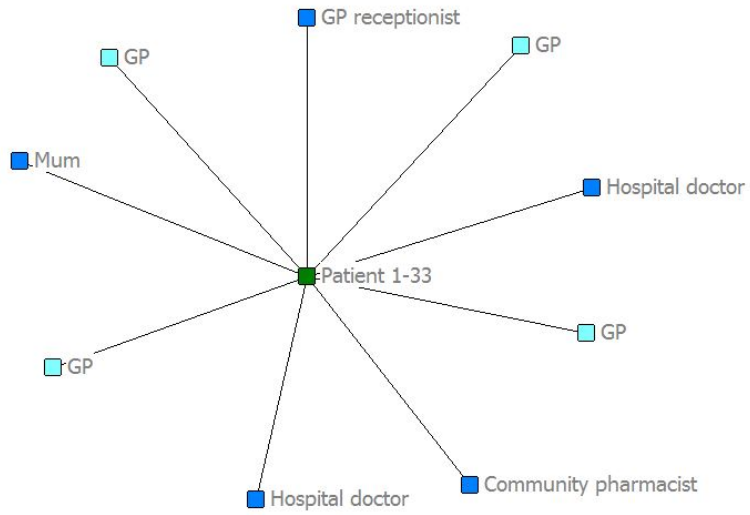


Figure 26: Sociogram of the ego-network for patient number 1-33.

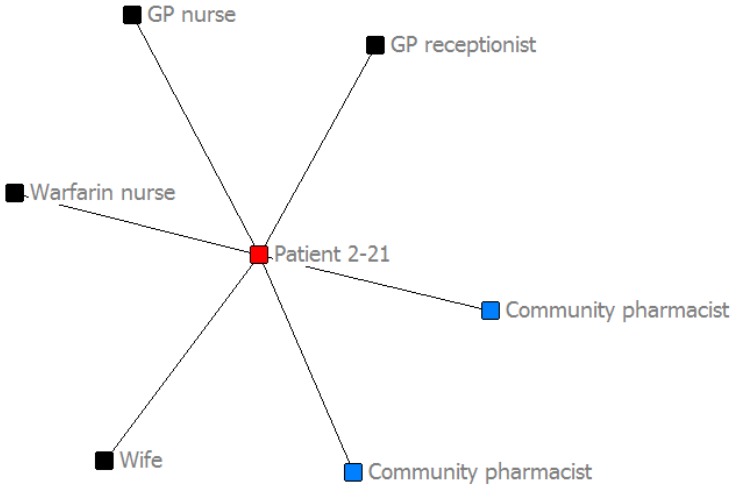


Figure 27: Sociogram of the ego-network for patient number 2.21.

A further type of professional contact described by patients was healthcare support staff. These contacts were pharmacy counter assistants, GP receptionists, pharmacy delivery drivers delivering medicines to patients' homes, or hospital administration staff. Forty patients had contact with 57 healthcare support staff members. Patients often experienced direct contact with healthcare support contacts in the course of accessing the instrumental [practical aid] functions of other healthcare professionals. For example, they

would have contact with GP receptionists, pharmacy counter assistants and pharmacy delivery drivers delivering to patients' homes in order to access medicines provided by GPs and pharmacists or to arrange appointments. Patients' professional contacts are shown in the composite sociograms in Figures 28–31 for males and female patients at Sites 1 and 2. They demonstrate the variation in experience of patients accessing professional medicines management services. For example, one male patient at Site 1 in Figure 28 used the healthcare services of two cardiac rehabilitation nurses (marked in cyan), but had no contact with any other professional alters. In the same figure, one patient's only contact after discharge was with a pharmacy assistant. Another male patient, in this case at Site 2, accessed their GP (marked in black) and a community pharmacist (marked in grey) whilst a further male patient at Site 2 accessed their GP and a cardiac rehabilitation nurse.

5.3.2 Personal (informal) ego-network alters

In addition to their professional medicines management alters, patients reported the presence of family members and friends in their medicines management networks. Forty-nine patients had medicines-related contact with 93 friends and family members. Family contacts included spouses, children, parents and siblings, whilst friends and neighbours and extended family members were also included in patients' medicines management networks. More distant relatives such as in-laws and cousins also featured along with other people patients knew but were not close to, for example acquaintances at church. Close relatives often lived nearby or with patients, and sometimes patients had moved in with relatives during their recovery. Figure 32 shows the sociogram of Patient 2.20. The parents of the patient were named as medicines management contacts and this patient had moved in with her parents after hospital discharge for temporary support whilst she waited for further treatment.

Some patients' personal alters also had healthcare experience, or were perceived by the patient to have such experience. Seventeen patients had contact with 17 such alters. Examples included wives who were nurses or former nurses, friends or relatives who were GPs, or extended family members and neighbours who were perceived to have medicines knowledge because of their current or former roles in health or social care.

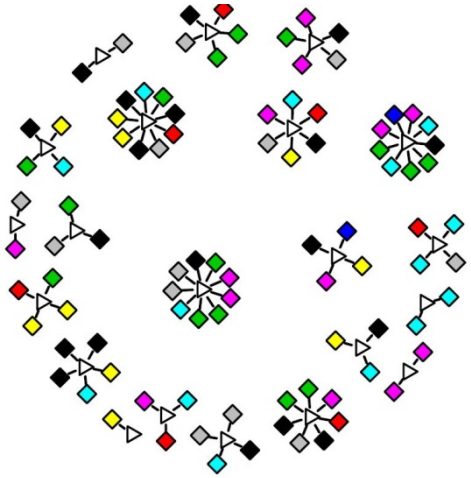
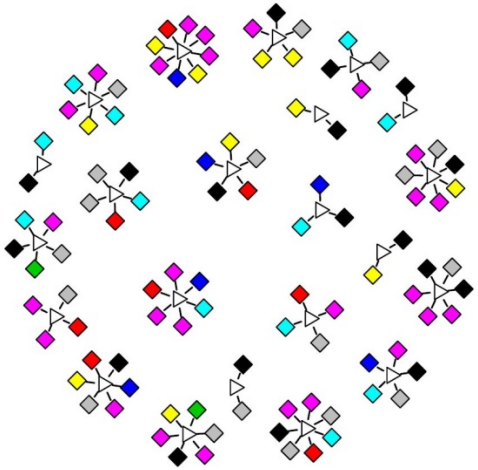


Figure 28: Site 1 male patients' professional networks.



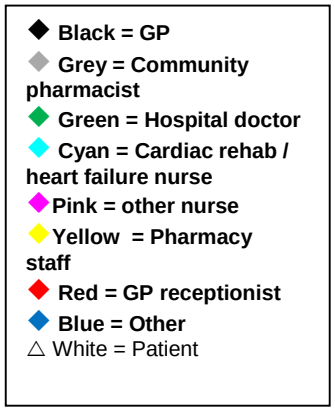


Figure 29: Site 2 male patients' professional networks.

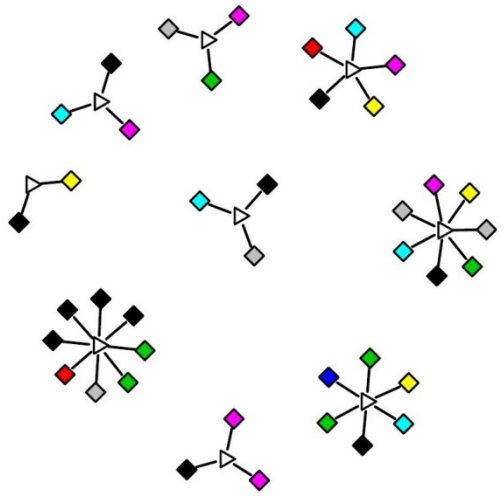


Figure 30: Site 1 female patients' professional networks.

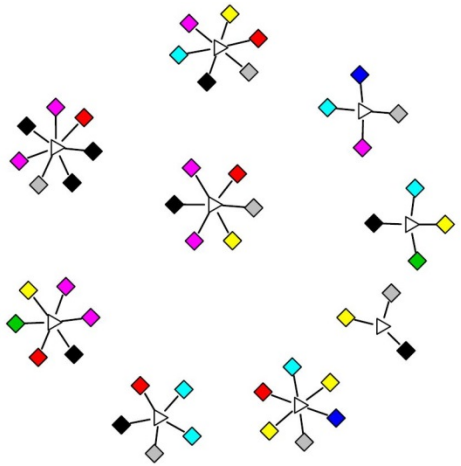


Figure 31: Site 2 female patients' professional networks

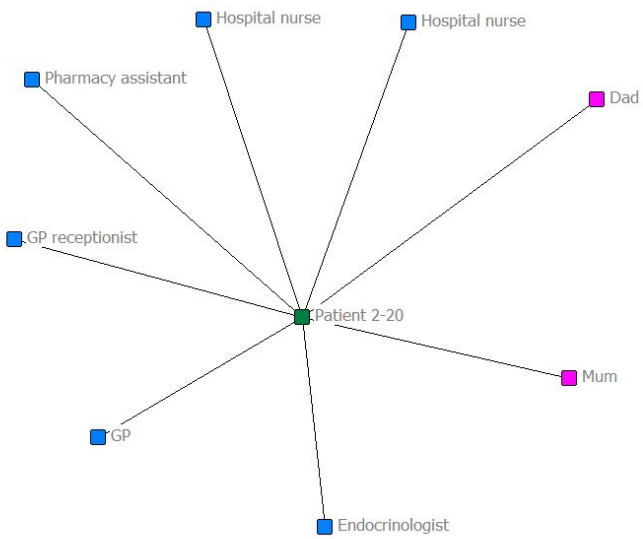


Figure 32: Sociogram of the ego-network for patient number 2.20.

For example, patients talked about family members who had managed care homes who knew about medicines because of their care management experience or of neighbours who were nurses.

Figures 33–36 are composite sociograms of the personal networks of male and female patients at different sites. They show personal network members with and without healthcare experience and demonstrate how some patients were isolated from personal medicines management contacts, whilst others had spousal and other friend and family network presence.

5.3.3 Ego similarity with personal alters

The concept of homophily in informal networks was explored between egos and their personal alters. Of the 43 male patients' 68 personal alters 70.6% (48) were female whilst 29.4% (20) were male. Of the 18 female patients' 42 personal alters, 54.8% (23) were female and 45.2% (19) were male. This indicates that there is a greater degree of gender homophily in female patients' personal networks than in males' personal networks.

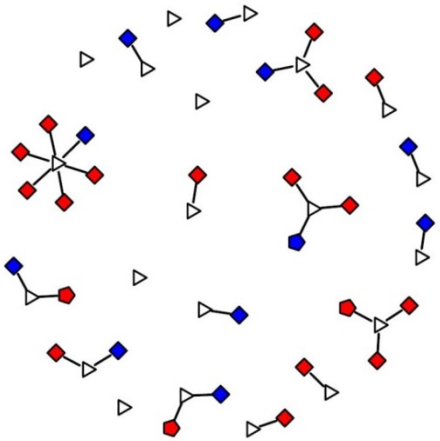


Figure 33: Site 1 male patients' personal networks.

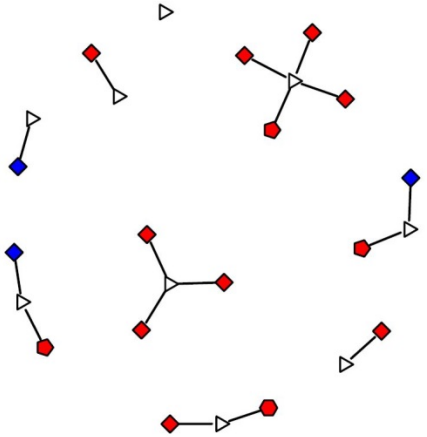


Figure 34: Site 1 female patients' personal networks.

△ Patient
◆ Blue = Spouse
◆ Other friends and family
△ Patient
◆◆ Four-sided shape = Personal contact
⬟⬟ Five-sided shape = personal contact with healthcare experience

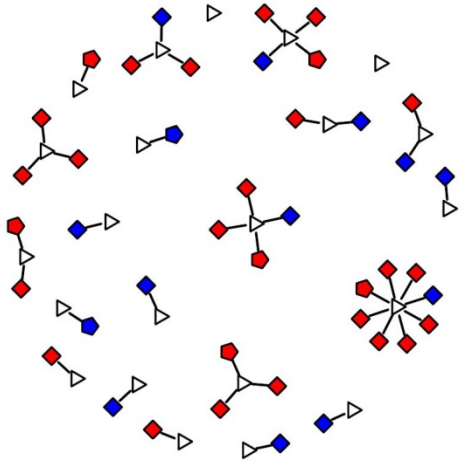


Figure 35: Site 2 male patients' personal networks.

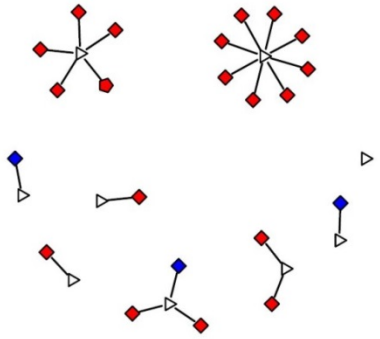


Figure 36: Site 2 female patients' personal networks.

To confirm this a gender E-I index was calculated,[335] which produced an overall index score of 0.42 for males and -0.01 for females. It is calculated by comparing the number of similar gender connections to the number of different gender connections. The calculation is positive when a group is dissimilar and negative when it is similar. The more positive score for males in the sample indicates how men reported women more frequently playing a role in medicines management than women reported men doing so.

5.4 Ego-network connectedness

This section explores patient perceptions of the connections between alters in their networks. During interviews, patients were asked if they perceived that their network alters were in contact with each other regarding their medicines. As data presented in Chapter 6 demonstrates, patients drew a distinction between passive receipt of information about their medicines and more active communication about them and their treatment. Patients' responses were analysed to give a measure of how connected their medicines management networks were and how much they acted themselves to join up their networks. The following analysis was conducted on the ego networks of 60 patients who were interviewed. One patient was unavailable for interview.

5.4.1 How connected are patients' ego networks?

The number of ties in an ego network is a measure of the number of connections among its alters (not including the ego). Because the ties are undirected, ties between alters are counted twice, representing two ties per connected alter pair. The mean number of ties perceived by patients in their networks was 5.28 (SD 9.26). The median and mode number of ties were both 2, indicating patients' perceptions of mostly limited contact amongst their network members about their medicines. A quarter of the sample (15) perceived no ties between their medicines management contacts and more men (11) than women (4) reported no ties between their network members. The maximum number of network ties reported was 58. These ties were perceived amongst the family members of a female patient whose brothers, sisters and mother all took similar medicines for their cardiology conditions. Figure 37 is a sociogram of this ego network clearly indicating the large number of ties amongst the patient's family members. This patient also perceived ties between two

professional members of their networks, in this instance between the cardiac rehabilitation nurse and her GP. No connections were perceived between the other professional members of her medicines management network, including her community pharmacist.

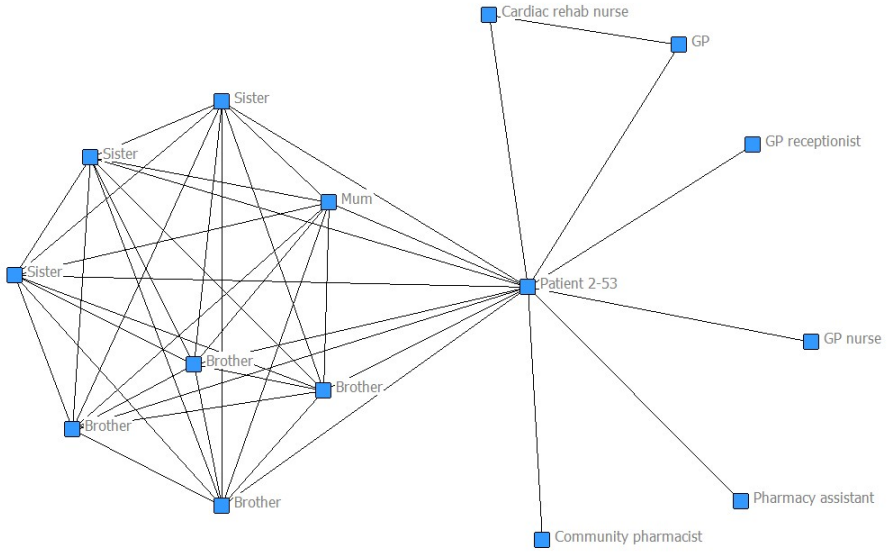


Figure 37: The ego-network of patient number 2.53 with 58 network ties.

Many patients perceived limited or no connectedness in their ego networks and these patients' networks often contained many alters. To illustrate this, Figure 38 is a sociogram of the ego network of Patient 1.1. This male patient recorded two healthcare professional alters and three personal alters in this network but perceived no ties between any of those alters. Patients tended to report limited connectedness between professional members of their networks, however patients perceived cardiac rehabilitation nurses and heart failure nurses more often than others to be in contact with other healthcare professionals concerning patients' medicines (see section 5.3.4). Other nurses and community pharmacists and other pharmacy staff were perceived by patients to be actively in contact with others less often.

5.4.2 Ego network density

The ‘density’ of a network is a single measure of how connected it is. Density is calculated by dividing the number of ties in the network (not including the ego) by the possible number of ties, giving a measure of the proportion of potential ties that are present. Tables 21–24 show the density of each patient’s ego-networks along with the number of ties in their networks and the number of potential ties. They show that on average women perceive slightly denser (more connected)

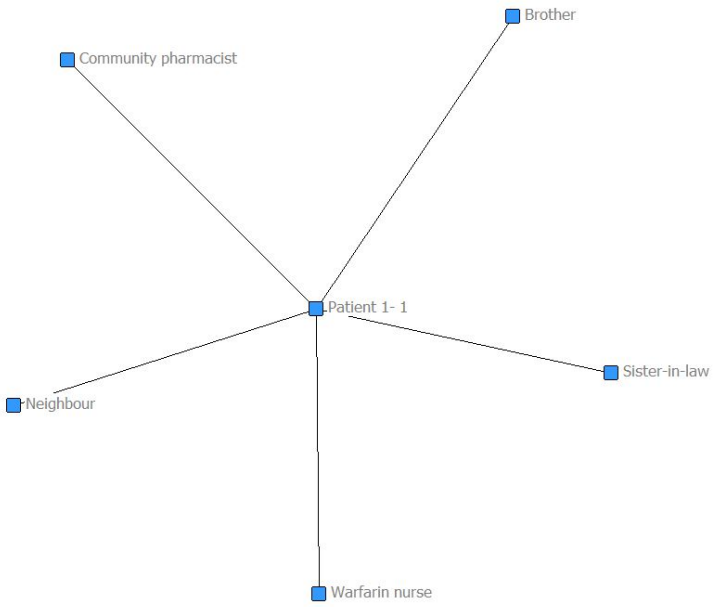


Figure 38: A sociogram of the ego network of Patient 1.1.

networks than men, although a series of two-tailed independent sample t-tests indicated no significant differences in the perceived density of men’s and women’s ego networks (t (58) = -0.979, p = 0.339 (equal variances not assumed). There were also no significant differences between the ego networks of those discharged from different hospital sites (t (58)= 0.798, p = 0.428). Using a Pearson correlation calculation, no significant correlation was found between ego network density and patient age (r = -0.203, p = 0.119).

Patients’ ego-networks were further analysed for the concept of ‘betweenness’. An ego is between other alters if they are positioned on the path between them. For example, if a patient perceives that they themselves are the conduit between their GP and community pharmacist then they are ‘between’ those two alters. The calculation of ‘normalised betweenness’ takes into account network

size to allow comparisons between networks. A patient who perceived no contact at all amongst alters in their network would have a maximum normalised betweenness measure. For example, this was the case for Patient 1-1 represented in Figure 38, in which all connections between alters are through the ego. Table 25 presents the betweenness range calculations for patients by site and gender and normalized betweenness means. Overall patients' networks were calculated to have high levels of betweenness, indicating their perceptions of poor connectedness between those who play a role in managing their medicines. Independent samples t-tests indicated no significant differences between males and females (t (57) = 0.830 (57), p = 0.415) and discharge site (t = 0.686 (57), p=0.492). Using a Pearson correlation calculation, no significant correlation was found between normalised betweenness and patient age (r = 0.128, p = 0.333).

Table 21: The density of male patients' ego networks at Site 1.

Patient	Number of ties	Number of possible ties	Density %
Patient 1-1	0	20	0.00
Patient 1-10	6	42	14.29
Patient 1-11	8	20	40
Patient 1-12	0	20	0
Patient 1-18	8	110	7.28
Patient 1-28	4	20	20.00
Patient 1-3	4	30	13.33
Patient 1-34	28	210	13.33
Patient 1-38	4	20	20.00
Patient 1-4	7	42	16.67
Patient 1-41	2	42	4.76
Patient 1-45	2	20	10.00
Patient 1-46	0	0	0.00
Patient 1-47	2	12	16.67
Patient 1-49	0	6	0.00
Patient 1-5	0	20	0.00
Patient 1-51	2	12	16.67
Mean (SD)	**4.35 (6.48)**	**35.30 (45.89)**	**11.04 (7.96)**

Table 22: The density of male patients' ego networks at Site 2.

Patient	Number of ties	Number of possible ties	Density %
Patient 2-1	4	72	5.56
Patient 2-10	34	132	25.76
Patient 2-11	0	6	0.00
Patient 2-12	8	42	19.05
Patient 2-13	0	6	0.00
Patient 2-14	6	42	14.29
Patient 2-15	0	42	0.00
Patient 2-16	4	42	9.52
Patient 2-18	2	30	6.67
Patient 2-21	2	30	6.67
Patient 2-23	2	20	10.00
Patient 2-24	0	12	0.00
Patient 2-26	4	30	13.33
Patient 2-33	2	72	2.78
Patient 2-35	18	90	20.00
Patient 2-4	2	30	6.67
Patient 2-5	0	6	0.00
Patient 2-50	6	56	10.71
Patient 2-52	2	30	6.67
Patient 2-6	4	56	7.14
Patient 2-8	10	90	11.11
Patient 2-9	0	2	0.00
Mean (SD	**5.00 (7.73)**	**42.64 (32.72)**	**8 (7.23)**

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Table 23: The density of female patients' ego networks at Site 1.

Patient	Number of ties	Number of possible ties	Density %
Patient 1-7	2	12	16.67
Patient 1-8	14	56	25
Patient 1-9	6	90	6.67
Patient 1-27	2	12	16.67
Patient 1-33	4	72	5.56
Patient 1-40	8	20	40
Patient 1-44	0	30	0
Patient 1-50	0	12	0
Patient 1-55	2	42	4.76
Mean (SD)	**3.56 (3.58)**	**37.56 (33.06)**	**12.70 (16.33)**

Table 24: The mean betweenness measures in the ego networks of patients by site and gender.

	Betweenness range	Mean normalised betweenness (SD)
All	**0 – 79.5**	**87.28 (12.80)**
Males Site 1	**0 – 79.5**	**86.53 (9.60)**
Females Site 1	**5 – 51.0**	**85.08 (20.56)**
Males Site 2	**1 – 39.5**	**90.01 (10.60)**
Females Site 2	**3.5 - 62**	**84.39 (15.02)**

Table 25: The density of female patients' ego networks at Site 2.

Patient	Number of ties	Number of possible ties	Density %
Patient 2-17	4	72	5.56
Patient 2-20	2	56	3.57
Patient 2-22	8	56	14.29
Patient 2-25	2	30	6.67
Patient 2-29	2	56	3.57
Patient 2-3	4	12	33.33
Patient 2-30	8	42	19.05
Patient 2-34	0	20	0.00
Patient 2-53	58	182	31.87
Mean (SD)	**9.78 (18.29)**	**58.44 (50.23)**	**13.10 (12.50)**

A brokerage measure calculated the extent to which the ego acts as a broker – or a go-between – in their network. A brokerage score measures the number of pairs in the network that are not connected; the normalised brokerage score divides brokerage by the number of pairs in the network. Egos who perceived no connectedness in their networks have high normalised brokerage scores because all the alters in the network must use the ego as a broker. Figure 38 depicting the ego network of Patient 1.1 demonstrates this brokerage role, in this instance the patient perceives themselves as a broker for all their alters so has a normalised brokerage score of 1. Patient 1.40 has the lowest normalised brokerage score of 0.60 and their ego network is depicted in the sociogram in Figure 39. This patient reported her cardiac rehabilitation nurse to have been in contact with her GP about her medicines and her husband, who managed her medicines for her, who also had contact with her GP. Her son also kept in contact with her husband concerning her medicines. Her community pharmacist, for whom the patient acts as a broker, is isolated in this ego network.

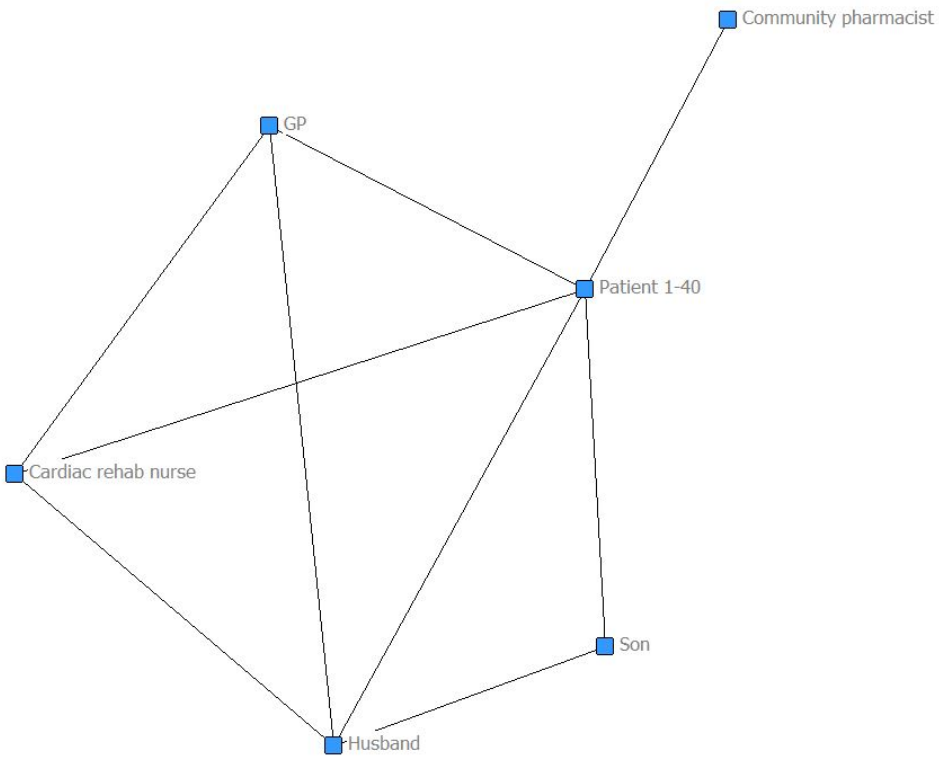

Figure 39: A sociogram depicting the ego-network of patient number 1.40 with a brokerage score of 0.60.

Data were then analysed for the number of ‘weak components’ present in each patient’s ego network. Weak components are a group of actors (or an individual actor) who are connected to each other and the ego, but not to others in the network. For example, if the patient has a connection to a GP and a cardiac rehabilitation nurse who are in turn are connected to each other, but they are not connected to any other actors in the network then they form a weak network component. This is important because it gives an indication of the number of groups of personal and professional contacts patients’ perceived as not being in contact and therefore the patient may have needed to take action to join them together. Groups of actors in weak components can be referred to as ‘cliques’. Patients’ networks had a mean of 4.48 (1.64) weak components and median of 4 weak components.

Patient 1.18 reported eight weak components in her network and Figure 40 is a sociogram depicting that network. In this instance the clique comprising the patient, the cardiac rehabilitation nurse and the hospital doctor, and the clique comprising two of the patient’s daughters and her nephew, form two weak components. Each of the other isolated alters form six further weak components.

Patient 2.30 reported three weak components in her network which are represented in the sociogram in Figure 41. In this case the patient perceived connectedness between many members of her network with a large group of healthcare professionals and her daughter forming one weak component whilst the community pharmacist and the pharmacy assistant form two further weak components.

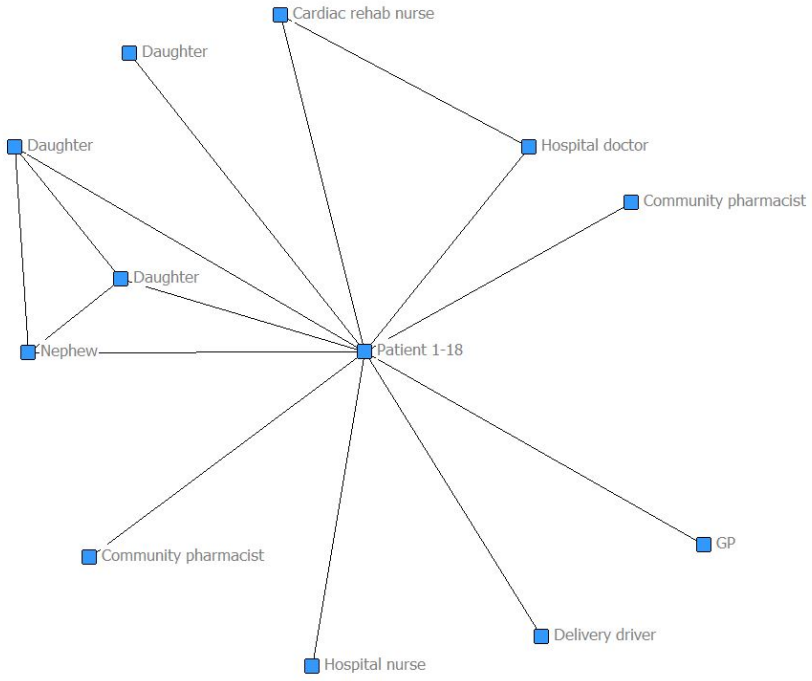

Figure 40: A sociogram of the ego-network patient number 1.18 showing eight weak components.

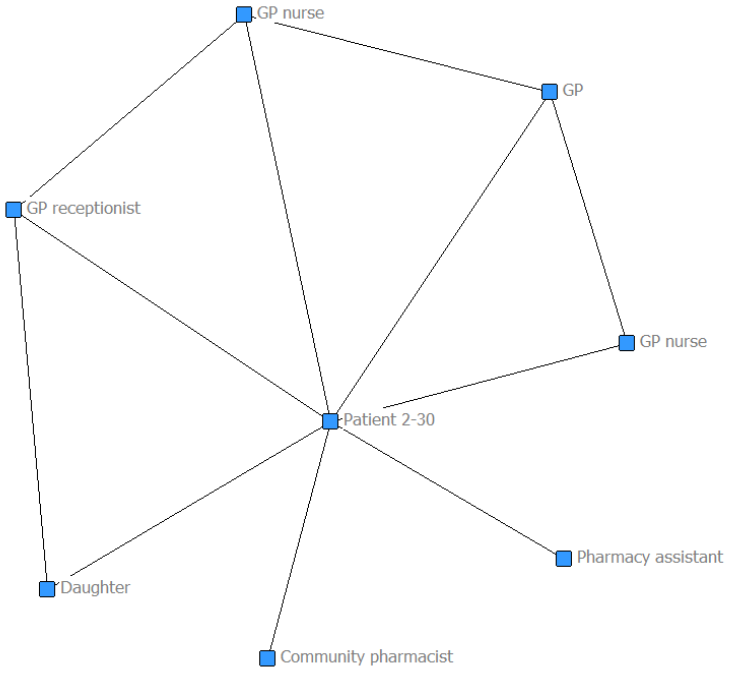

Figure 41: A sociogram of the ego-network of patient number 2.30 showing three weak components and isolated community pharmacy staff.

Brokerage and weak component calculations are presented for all patients in Tables 27–30. A series of two-tailed independent sample t-tests and Pearson correlation tests indicated that there were no significant differences between males and females or between patients discharged from different sites. The results of these tests are shown in Tables 31–32. The calculations indicate very loosely connected networks with patients perceiving themselves in strong brokerage roles between their network alters. Patients' mean brokerage was 18.25 (SD 16.53) with a mean normalised brokerage calculation of 0.88 (SD 0.15). On average there were 4.48 (SD 1.64) weak components in each patients' ego network and 74.70% (SD 20.60) of patients' ego networks comprised weak components. Weak components in the networks indicated the extent to which patients themselves bridged groups of personal and professional alters.

5.4.5 Density measures of professional alters

Calculations were made for the density of other HCP and healthcare support alters in patients' ego-networks to offer a comparative measure of how integrated patients perceive different types of HCP and healthcare support are in their medicines networks. The mean value for each group is presented in Table 26. Cardiac rehabilitation nurses were perceived to be the most integrated professional network members followed by GPs and hospital doctors. It is likely that the density measures for GPs and hospital doctors are increased by perceived contact with cardiac rehabilitation nurses because these ego-networks are undirected. Community pharmacy staff, GP receptionist and other nurses are the least connected HCPs, as perceived by patients. These values indicate the extent to which patients believe their care to be co-ordinated by the professionals involved in it.

Table 26: Density measure for professional groups

Role	Average density
Cardiac rehabilitation / Heart failure nurses	**0.59**
GPs	0.48
Hospital doctors	0.42
Community pharmacists	0.31
GP practice nurses	0.30
Community pharmacy drivers	0.27
GP receptionists	0.25
Other nurses	0.23
Community pharmacy staff	0.10

Table 27: Brokerage and weak component scores for males at Site 1.

Patient	Brokerage	Normalised brokerage	Weak components	Proportion of weak components
Patient 1-1	10	1.00	5	100.00
Patient 1-10	18	0.86	5	71.43
Patient 1-2	9	0.90	4	80.00
Patient 1-20	5	0.83	3	75.00
Patient 1-23	10	1.00	5	100.00
Patient 1-28	8	0.80	3	60.00
Patient 1-3	13	0.87	4	66.67
Patient 1-34	91	0.87	5	33.33
Patient 1-38	8	0.80	3	60.00
Patient 1-4	17.5	0.83	3	42.86
Patient 1-41	20	0.95	6	85.71
Patient 1-45	9	0.90	3	60.00
Patient 1-46	0	0.00	1	100.00
Patient 1-47	5	0.83	3	75.00
Patient 1-49	3	1.00	3	100.00
Patient 1-5	10	1.00	5	100.00
Patient 1-51	5	0.83	3	75.00
Patient 1-7	5	0.83	3	75.00
Patient 1-8	21	0.75	4	50.00
Patient 1-9	42	0.93	7	70.00
Mean	**15.48**	**0.84**	**3.9**	**74**

Table 28: Brokerage and weak component scores for males at Site 2.

Patient	Brokerage	Normalised brokerage	Weak components	Proportion of weak components
Patient 2-1	34	0.94	7	77.78
Patient 2-10	49	0.74	4	33.33
Patient 2-11	3	1.00	3	100.00
Patient 2-12	17	0.81	3	42.86
Patient 2-13	3	1.00	3	100.00
Patient 2-14	18	0.86	4	57.14
Patient 2-15	21	1.00	7	100.00
Patient 2-16	19	0.90	5	71.43
Patient 2-18	14	0.93	5	83.33
Patient 2-21	14	0.93	5	83.33
Patient 2-23	9	0.90	4	
Patient 2-24	6	1.00	4	100.00
Patient 2-26	13	0.87	4	66.67
Patient 2-33	35	0.97	8	88.89
Patient 2-35	36	0.80	4	40.00
Patient 2-4	14	0.93	5	83.33
Patient 2-5	3	1.00	3	100.00
Patient 2-50	25	0.89	5	62.50
Patient 2-52	14	0.93	5	83.33
Patient 2-6	26	0.93	6	75.00
Patient 2-8	40	0.89	6	60.00
Patient 2-9	1	1.00	2	100.00
Mean	**18.82**	**0.92**	**4.64**	**76.77**

Table 29: Brokerage and weak component scores for females at Site 1.

Patient	Brokerage	Normalised brokerage	Weak components	Proportion of weak components
Patient 1-11	6	0.60	2	40.00
Patient 1-12	10	1.00	5	100.00
Patient 1-18	51	0.93	8	72.73
Patient 1-27	5	0.83	3	75.00
Patient 1-33	34	0.94	7	77.78
Patient 1-40	6	0.60	2	40.00
Patient 1-44	15	1.00	6	100.00
Patient 1-50	6	1.00	4	100.00
Patient 1-55	20	0.95	6	85.71
Mean	**17**	**0.87**	**4.78**	**76.80**

Table 30: Brokerage and weak component scores for females at Site 2.

Patient	Brokerage	Normalised brokerage	Weak components	Proportion of weak components
Patient 2-17	34	0.94	7	77.78
Patient 2-20	27	0.96	7	87.50
Patient 2-22	24	0.86	4	50.00
Patient 2-25	14	0.93	5	83.33
Patient 2-29	27	0.96	7	87.50
Patient 2-3	4	0.67	2	50.00
Patient 2-30	17	0.81	3	42.86
Patient 2-34	10	1.00	5	100.00
Patient 2-53	62	0.68	6	42.86
Mean	**24.33**	**0.87**	**5.11**	**69.09**

Table 31: t-test results for brokerage and weak component scores by site and gender.

	Brokerage	Normalised brokerage	Weak components	Proportion of weak components
Site	$t(58) = -1.048$ $p = 0.299$	$t(58) = -0.798$ $p = 0.428$	$t(58) = -1.432$ $p = 0.157$	$t(58) = 0.61$ $p = 0.952$
Gender	$t(58) = -0.736$ $p = 0.465$	$t(58) = 1.228$ $p = 0.224$	$t(58) = -1.437$ $p = 0.156$	$t(58) = 0.427$ $p = 0.671$

Table 32: Pearson's correlations for brokerage and weak component scores and patient age.

	Brokerage	Normalised brokerage	Weak components	Proportion of weak components
Age	$r = -0.051$ $p = 0.697$	*$r = 0.203$* *$p = 0.119$*	$r = -0.053$ $p = 0.672$	*$r = 0.184$* *$p = 0.159$*

5.5 Medicines management alter value to patients

During interviews, patients were asked to rate the value of each alter to them in managing their medicines. They did so by placing the contact on an egocentric mapping tool made up of concentric circles marked with numbers 1–4. If they positioned alters closer to the centre they perceived them to be more valued. The concept of value was also explored with patients, who explained why they had placed certain alters in higher value positions of their maps. Their decisions about high value were made either because the alter was essential to them in providing or organising medicines, because they were perceived as efficient, because they were at the top of patients' perceived professional hierarchy, or because patients perceived that the alter had time for them. Ego-networks for all patients are presented in the sociograms in Appendix 3 in which the lines connecting egos to alters are thicker where the tie was reported as more valued by each ego.

Patients valued their friends and family with healthcare experience more highly than other alters in their network. Healthcare professionals and patients' friends and family members without healthcare experience were valued similarly highly, whilst healthcare support staff were the least valued category of alter. The radar plot in Figure 42 shows the comparative mean value of alter types to patients.

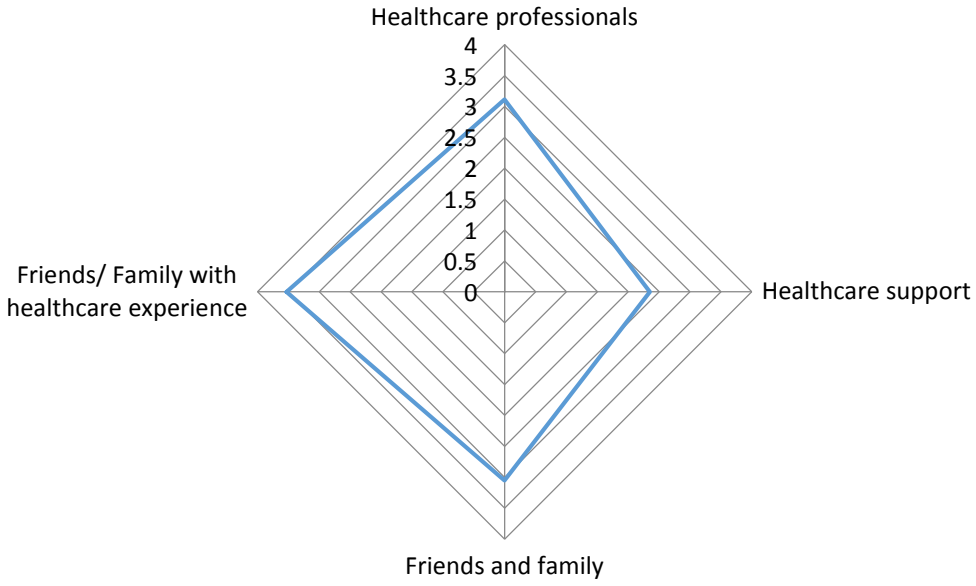

Figure 42: A radar plot showing the comparative mean value of alter types to patients.

Patients' ratings of their alters were dichotomised to give a binary indication of high and low values. Figure 43 is the proportion of alters by type who were highly valued (scores 1 or 2) by patients. In the overall sample nearly three quarters of patients' healthcare network members (72.9%) were valued highly by patients and therefore are classified as strong ties, fewer healthcare support staff (47.4%) than other alter types were highly valued by patients. A higher proportion of cardiac rehabilitation or heart failure nurses were highly valued than any other healthcare professional. More GPs than community pharmacists were highly valued, whilst GP receptionists were the least highly valued medicines management contact. Over two thirds (68.8%) of network alters who were classified as friends and family were highly valued by patient and nearly all friends and family with healthcare experience (94.1%) were highly valued by patients. Whilst hospital doctors were present in the networks of females at Site 2 none were highly valued.

A Pearson chi-square test with a Fisher's exact test correction revealed a significant association between the type of network member and the strength of the tie (X^2 (3) = 18.601, p<0.001). Exploration of the standardised residuals indicated that significantly fewer healthcare support staff were reported by patients to be highly valued than other alter types. Cramer's V indicated a small effect size of 0.22 (values range between 0-1).

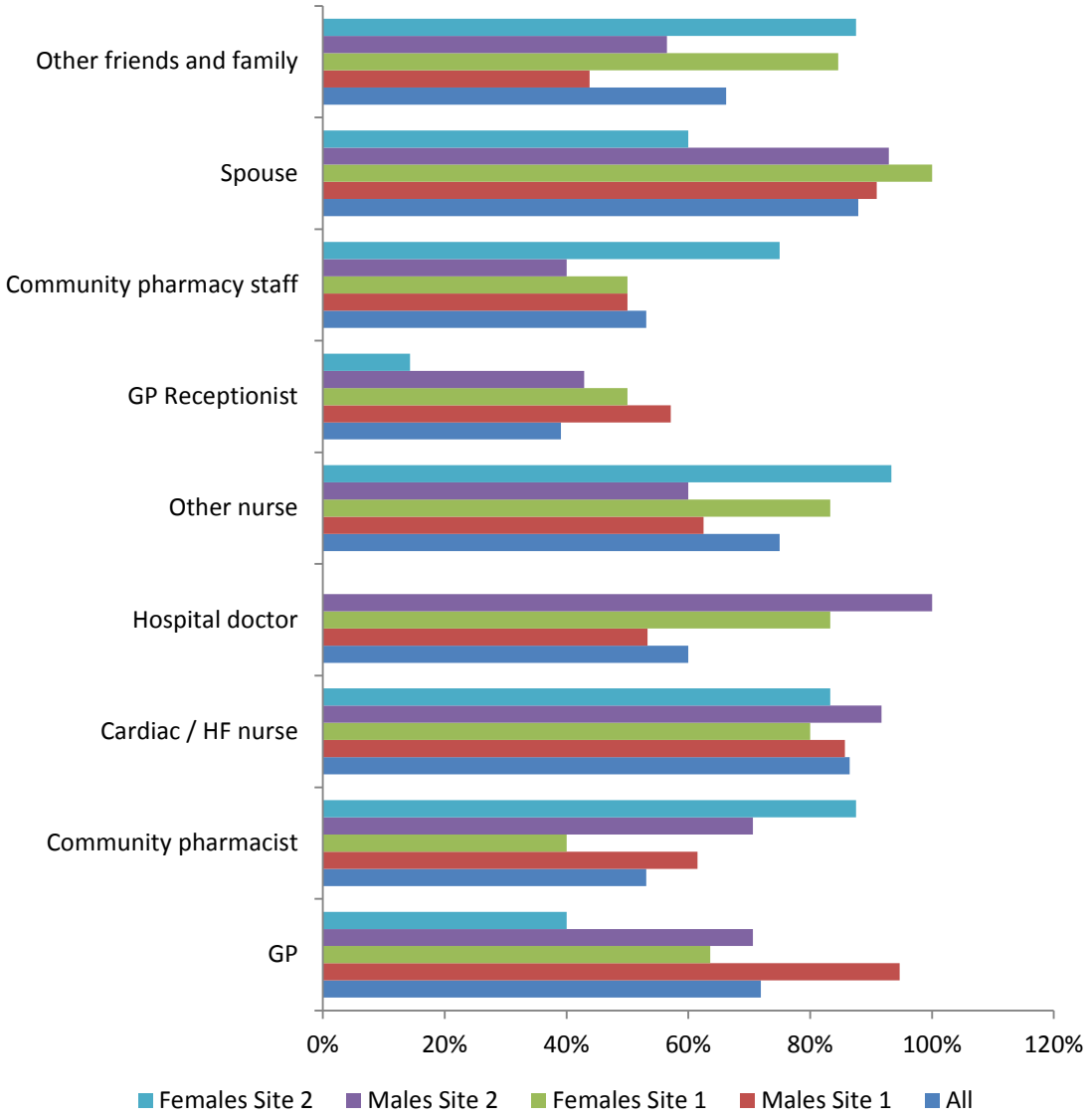

Figure 43: The proportion of network member types reported as highly valued by patients by site and gender.

5.6 Discussion

Patients had discharge medicines management networks of different sizes and compositions. They comprised healthcare professionals, healthcare support staff, and personal network members. The majority of network members were those providing formal healthcare services to patients and some patients had personal network members who were current or former healthcare professionals, who were highly valued by patients. Nurses, GPs and community pharmacists were the most commonly reported network alters and 45 patients had contact with one or more GPs. Community pharmacists were also present

in the networks of 36 patients. Patients perceived limited contact between their professional alters, however, cardiac rehabilitation nurses were considered the most connected professional group. Community pharmacy staff, GP receptionists and other nurses were perceived as the least connected professional alters. GPs and cardiac rehabilitation nurses were frequently highly valued by patients whilst spouses were more frequently highly valued than other personal network members. On average, personal contacts with perceived healthcare experience were perceived as the most valuable network types.

Through the novel application of Social Network Analysis, and specifically an ego-network approach, it has been possible to develop an understanding of the structure of medicines management viewed from the patient perspective as the patient perceived it, rather than as it is designed by policy or perceived to exist by healthcare professionals. It has highlighted how patients are at the centre of different compositions of professional and personal networks and it has demonstrated that those networks are sometimes large and diverse. It has also raised questions about the extent to which patients perceive their medicines management is currently co-ordinated. The data suggest that there are no consistent pathways to help patients with their medicines once they leave hospital. Whilst this in part reflects individual variation in patients' care needs, after leaving hospital one in four patients had no contact with a GP who may be expected to have an overview of the care patients receive from different healthcare professionals and the different treatments prescribed for different chronic conditions.[336] NICE stresses how medicines optimisation should be focussed on the involvement of all HCPs and social care professionals involved in the patient's care and that professional collaboration across healthcare settings is required.[72] This research shows that patients do not perceive their GPs were actively managing polypharmacy and their care co-ordination role may well be limited to processing communication from different sources. NICE suggests that healthcare providers consider sending discharge medicines information to a nominated community pharmacy; however this is not a required part of the pathway.[72] It is therefore difficult to ascertain what thought is given to patients' hospital discharge and medicines by somebody in primary care looking across patients' co-morbidities and their subsequent appointments with specialists. For some patients cardiac rehabilitation nurses to some extent

acted in a boundary-spanning role, hence their higher density measures in patients' ego-networks when compared to other HCPs and healthcare support staff.

Personalisation of and participation in healthcare is also a current NHS agenda.[22] This data demonstrates that care is individualised to each patient, however there is no evidence that it is designed around them as individuals, as discussed further in Chapter 8. Patients receive care from different professionals, but the extent to which their medicines optimisation care is planned for them after they leave hospital is unclear. NICE now recommends that medicines optimisation services are patient-centred in that they take into account individual needs and preferences.[72] Implementing a clear pathway for accessing professional medicines support following discharge from hospital which is common to all patients and communicated clearly to them would help orientate patients and would ensure medicines information came from the most relevant professional group.

Contact with community pharmacy

Many patients in this study had no contact with a community pharmacist following their discharge. Several initiatives are underway in the UK to direct patients to community pharmacy to provide additional support;[111,327,337,338] yet, as in previous work, our research indicates more needs to be done to integrate community pharmacy into care pathways and consolidate the value of clinical community pharmacy services for patients.[116] Europe-wide, community pharmacy has identified medicines-related problems in nearly two-thirds of patients after their discharge from hospital and pharmacists were able to intervene through educating patients or communicating with the medicines prescriber.[125] Formal structured interventions, such as post discharge medicines review for patients with heart failure, can contribute to patient safety by uncovering post-discharge medicines problems;[130] however they are not universally implemented. Interventions performed specifically by community pharmacists are thought to be beneficial, particularly in identifying medication errors;[129] however there is a lack of high quality studies to conclusively demonstrate this.

As described in Chapter 6, few patients in this study underwent an MUR after their discharge and this chapter demonstrates the comparative isolation of community pharmacists and community pharmacy staff in the eyes of patients. If community pharmacy services are to be successfully integrated into the care pathway that patients follow once they leave hospital, a consultation should occur by default, rather than relying on the community pharmacy to notice that the patient has been recently discharged to have the opportunity to conduct a review, or on the patient to request help. The purpose of the review needs to be made clear to patients, which Chapter 6 will show does not always happen, and they should be given guidance about how to prepare for it. Importantly, they should be able to find out the outcome of any recommendations the pharmacist might make to their GP about their medicines. Community pharmacists also need to explore how they can better engage with patients to produce better outcomes from treatment. This chapter has shown that patients may engage with pharmacy delivery drivers delivering to their homes and community pharmacy staff who may act as a proxy for contact with a community pharmacist and Chapter 6 will show that community pharmacy may miss opportunities to meaningfully engage with patients. Taking steps to facilitate a more supportive encounter would reflect more closely the professional vision for community pharmacy's role in optimising patients' medicines.

Many patients reported being invited to access cardiac rehabilitation and heart failure nurse services, which are services that provide individual care, sometimes in the patient's own home. Eligibility and waiting times for these services are increasing nationally and the number of patients with co-morbidities that access them is also increasing.[339] Those that did not have the opportunity to access them may not have been given the opportunity to discuss their medicines in detail with a healthcare professional after leaving hospital. The multi-professional context in which patients experience their care, as demonstrated in this chapter, may lead to patients not fully understanding the roles that different practitioners may play. Because patients do not automatically have contact with a community pharmacist after their discharge and many do not see their GP, opportunities to support their medicines use may be missed. The findings of this study show how the divide between patient service

providers places patients in brokerage roles at a time when they are likely to be ill and vulnerable after being in hospital and which they may or may not perceive as burdensome. It is accepted that poor coordination of healthcare providers can lead to discrepancies between the medicines lists held by different care providers and the medicines that the patient actually takes when they are leave hospital.[72,94,95] At present in the UK community pharmacy does not receive patients' medicines lists by default after leaving hospital, so incorrect medicines could be prescribed by GPs and not identified by community pharmacists. There are, however moves to allow community pharmacy access to patients' summary care records, which gives concise information about current medicines, adverse reactions and known allergies.[123]

The role of informal carers

The role of informal carers and the problems they experience in medicines management has long been acknowledged.[340–342] It is clear from this research that alongside patients and healthcare staff many other personal contacts play highly valued roles in medicines management, and so a greater focus on supporting and integrating them into the patient pathway may be appropriate. It may also be appropriate to ask patients when they are in hospital about who will be managing their medicines once they are discharged so that person can be appropriately prepared by the hospital to manage the patients' medicines or support the patient in self-managing once they return home. This study has also identified a 'hidden' network of informal professional support in the form of friends and family members who patients reported having some healthcare experience and are perceived to have enhanced knowledge because of a current or former role. Over a quarter (17) of patients reported having these alter types in their networks. Some were qualified HCPs, such as nurses and doctors, others had run care homes in the past and patients perceived them to know about medicines because of this. Other research has identified the presence of such people in patients' networks but not discussed the risk that this might pose to patients.[248] If patients are in receipt of information or advice about their medicines from a hidden network then their behaviour towards their medicines may be modified as a result of this contact that sits outside the formal healthcare system. For example, they may not seek advice about a side effect if they have been told by someone they perceive to have enhanced healthcare

knowledge that that side effect is acceptable or normal, which is evident in the results of qualitative semi-structured interviews in the following chapter. Other perspectives have viewed access to an expert in an individual's social network as enhanced social capital;[343] for the patient this may be a more conveniently accessed and more approachable source of perceived expertise. No research has been found that looks at this phenomenon in within the context of patient safety or medicines safety.

This chapter has presented the structure of patients' medicines management ego-networks and explored the impact of those structures on the quality and safety of care. The following chapter will build on those results by describing the content and function of patients' medicines management networks.

Chapter 6 – The content and function of patients' medicines management networks

6.1 Introduction

This chapter presents the results of the qualitative thematic analysis of patient diary data and the semi-structured interviews that were conducted with patients approximately six weeks after their discharge from hospital. It aims to answer the following questions:

- What medicines management content do patients perceive in their ego-networks?
- What medicines management functions do patients perceive professionals and others to perform?

It is presented in two main sections:

- Ego-network content – exploring what flows between actors in the network; and
- Ego-network function – exploring the roles that the network performs.

The results are presented as a narrative describing the themes and subthemes in the data supported by quotes from patients. Quotes are referenced using a patient identification number which is prefixed by either the number 1 or 2, indicating which site the patient was from (for example 1.33 indicates site 1 patient 33).

6.2 Ego-network content

The content of patients' ego-networks comprises the substance of the interactions between network actors. The content of patients' ego-networks is presented in three main themes and nine subthemes as shown in Figure 44. The main thematic areas are: information and advice; attitudes and experiences; and requests and offers.

6.2.1 Information and advice

The theme of *Information and advice* is presented in four sub-themes: *Medicines information*; *Advice about taking medicines*; *Patient-provided information*; and *HCP information sharing*.

6.2.1.1 Medicines information

Much of the content of interactions between patients and their alters was information about medicines. Some patients obtained this actively and some passively to augment or fill gaps in the information given to them in hospital. For example, one patient described their community pharmacist *"putting me right"* (2.26) about the correct use of a GTN spray a few days after hospital discharge.

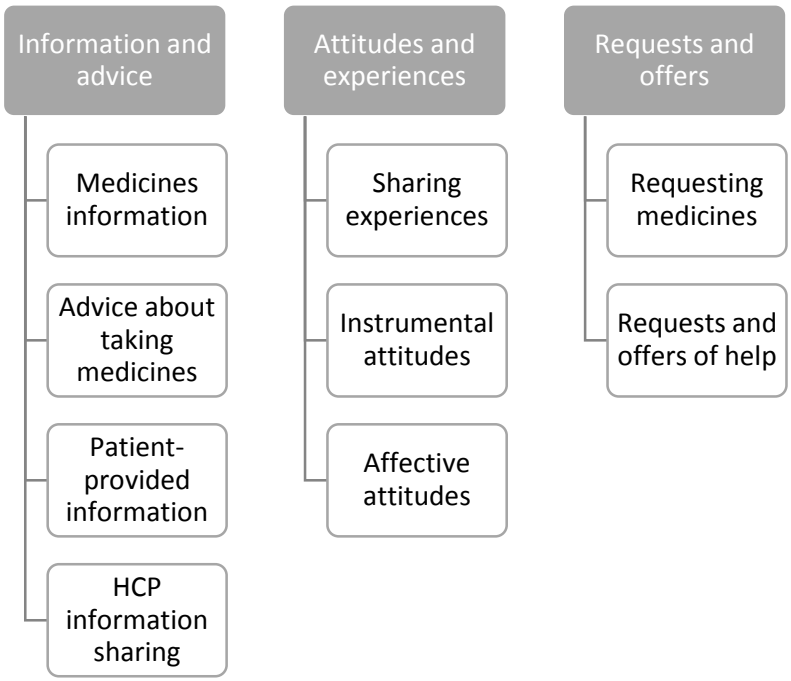

Figure 44: Medicines management network content

Some were able to recall information given to them in hospital, yet many described not receiving detailed or adequate medicines information before leaving hospital or they had forgotten what they had been told there about their medicines. One patient described himself as *"in the dark" (*1.21) because he had not received explanations about his medicines in hospital, which were *"never discussed or named to me".* Many explained how frustrating they found the lack of information given to them and described being treated dismissively.

"Well I'd say I don't think I was really given information [about my medicines in hospital], it was just a matter of, "Here's your tablets, sod off." (1.1)

Others explained that the written discharge summaries they were given were not designed for their use and were therefore of limited help once they returned home. For some patients hospital was not the ideal place to receive medicines information because of their poor health or their focus on returning home: one

patient described their preference to return to hospital to discuss their health and treatment at later date.

"Of course, lying in a hospital bed not feeling very well is not always the best time to ask questions. So from a personal thing it might have been nice to have gone back after a fortnight and just had a chat with somebody on the cardiac ward about what was going on." (1.2)

Patients received factual information about their medicines from network alters after their discharge. Patients reported how GPs, community pharmacists, GP practice nurses and specialist nurses – such as cardiac rehabilitation nurses, heart failure nurses and warfarin nurses – offered information about the purpose of medicines, although they occasionally found this information conflicted. In one case the patient had received information from his GP, who was a GP with Special Interest (GPSwI) in cardiology, about a safe dose of bisoprolol that was different to that given by the hospital.

"The GP cardiac specialist [GPwSI] appeared to think actually you know, it's not that big a deal just going over the 10mg, whereas the hospital was a lot more careful about it, saying no, we really shouldn't go over the 10mg unless you're here then we can monitor you." (1.8)

Specialist nurses, such as cardiac rehabilitation nurses, were described by patients as giving information about new medicines, when to use medicines and effects to watch out for *"fully and clearly*" (1.9). Another patient reported a cardiac rehabilitation nurse visit as:

"Over an hour of questions and information. Explained how the tablet dosages would alter over time and the reason for taking the different drugs." (1-45).

Other specialist nurses were reported to give information about the impact of lifestyle choices on the effects of medicines and future treatment. For example, Warfarin nurses gave information about the impact of drinking alcohol on the time it took the blood to clot.

Despite this, patients discussed specific types of information they lacked, explaining that they would like more information about the length of time they

would be required to take their medicines for, the long-term impact of their treatment or the combined effect of their medicines and how they would benefit from more information.

"Well, short-term, I think they [my medicines] are okay, and… so short term, they're working but I'm just wondering long-term, what will happen then." (2.12)

"I think, yes, it would be a step forward in giving a bit more…that bit more information and that…so you've…and then you know that that backing is there for you to…" (1.1)

These gaps were often described in more detail by patients and included the purpose of their medicines, how those medicines worked together to help their conditions and how long they should take them. Some patients thought information was not tailored to them. Others wanted more information specifically about the risks their medicines exposed them to.

"Well, yeah, I trust them that they do work well with other medicines, I trust them that far, but I'd like to know if there's any danger attached to them, you know. In a certain way, in a way, I don't, because I don't want to know, because I'd start being paranoid about it, and think I can't take that today, you know." (2-12)

Some used the internet to fill information gaps: in one case a patient described trying to match the side effects they perceived with information about side effects online.

"Well it [getting information] would have been helpful yeah, but I just did it myself, I came home and looked on the internet to find out what they were for and what they did, yeah. (1-27)

GP receptionists sometimes acted as conduits of information from GPs to patients. For example they would inform patients that GPs required them to obtain blood tests or that the GP wanted them to discontinue a medicine. GPs themselves, along with GP practice nurses and specialist nurses, would give patients information about test results and subsequent changes to their medicines.

HCPs offered information about side effects or potential adverse effects they may experience. These HCPs included GPs and hospital nurses, specialist nurses and community pharmacists.

"*Well she [the heart failure nurse]… said about things… you see, what's happening with some of my tablets, they're affecting my kidneys…And she [said] like Furosemide can affect your kidneys."* (2-25)

Community pharmacists played a role in providing information about side effects to a few patients who described attending medicines use reviews (MURs), for example one patient described being given basic information about side effects.

"She [the pharmacist] said you might get side effects and you might get a cough." (1-40)

HCPs also offered information that helped patients understand the effects they had experienced. One patient talked about his chest pains since leaving hospital and that a hospital sister explained that his long-term use of aspirin may be causing his discomfort and he should see his GP about prescribing a proton pump inhibitor. Another patient described being given information by their GP explaining how their medicines caused swollen ankles or had the potential to cause organ damage.

"In fairness to [my GP] he's explained, it's like my ankles are atrocious at swelling up and again, that's something new. Now what he said is it's the medication that unfortunately, the job of the medication is to divert the blood flow to the heart and keep that pumping and then what happens is, there is, you know something suffers and unfortunately it's my legs. It's the circulation." (1.44)

However, some lacked information about medicines side effects because this had not been offered to them in hospital or by other professionals they had seen since they had been discharged. Occasionally patients were unwilling to seek information about side effects because they believed it would have a psychological impact on them and their health.

"I don't want to know side effects because I always think, this is just me, I think if you see these side effects then it will affect you and if I don't know what the side effects are I'm not going to expect them, so I don't want any side effects. And touch wood I haven't had any that I know of. So I don't really want to know." (2.17)

Patients also obtained information about side effects from their friends and family who worked in healthcare. Information included what side effects to expect from medicines.

"The funny thing that happened is the statin everyone complains that the pains the first two weeks, right deep inside my legs, and I thought "crikey" and my brother-in-law said, oh that's normal." (2.35)

6.2.1.2 Advice about taking medicines

Patients received advice from HCPs about adhering to their medicines, strategies to help them adhere or strategies to reduce the impact of side effects. One patient described how a cardiac rehabilitation nurse advised him to take one of his medicines with a glass of orange juice to allay the headaches he experienced. Another was advised to take paracetamol to treat headaches caused by nicorandil, which is a medicine used to treat angina. A further patient reported getting advice from their community pharmacist during a MUR about not omitting taking medicines

"I gave them the medicine prescription and she told me like the, before she handed to me in the medicines and she called me into the small room and she explained me do you know what the reason these are medicine for you... and she goes you got to take these, you don't have to miss them." (1.10)

Cardiac rehabilitation nurses, community pharmacists and warfarin nurses also offered advice about the timing of medicines to help patients get the optimal effect or what to do in case a dose was missed by the patient. Some patients explained they did not need advice from community pharmacists if they were able to ask their GP for advice, indeed some emphasised that it was the GP's and not the community pharmacist's responsibility to give them medicines advice.

"If I need to ask some questions [about my medicines]…like I said, I don't discuss with them, pharmacists, it's mostly doctors." (1.38)

"Well there was various reactions I had with them to start off with, they weren't good and couldn't sleep at one point with one of the medicines and there's a cardiac nurse that comes round and she explained that if I took it in the morning instead of the evening it would probably be better than it was." (1.41)

Patients' personal network members with healthcare experience also gave advice, for example one patient's nephew, a GP, advised her to keep track of her blood pressure and to review her medicines with her own GP after she complained of feeling light-headed. Other personal network members made helpful suggestions to patients about the storage and organisation of their medicines.

"My daughter suggested [getting a compliance aid] because she's working as a nurse in the community, so she knows the patients that are on them. (2.12)

6.2.1.3 Patient-provided information

Patients described proactively giving information to their HCP contacts about the medicines they needed. They did this using several channels, including over the phone to GP receptionists, and via email.

"I just went, because I do it online, so I just emailed the surgery and wrote down everything I needed, what they'd [the hospital] said I was on permanently and they just did it." (1.27)

Others talked about how they were able to tell HCPs about how they were feeling about their medicines and offer them information about the side effects they perceived.

"I mean these muscle pains and joint pains I've never had before so there must be something to do with the drugs. It's a case of go and discuss it with the nurse and try a different dose or something, a different drug. (1.45)

Patients phoned or spoke face-to-face with GP receptionists in order to obtain repeat prescriptions. In some cases patients would communicate important

information about new or changed medicines to receptionists, about medicines that had been incorrectly supplied, or tell them what medicines supplies or devices were needed to ensure they had adequate supplies and to prevent the inadvertent continuation of medicines that should have been stopped.

"But actually thinking about it, no the next time I rang the receptionist and we went through them, she said Candesartan was still on the receptionist's list as an available repeat and I said no you can scrub that, so they ended up tidying a couple of.." (1.8)

Patients would sometimes tell GPs or other clinicians, such as specialist doctors, about the medicines they were taking in order to ensure those professionals were fully informed about their current treatment regime. Some explained that their complicated polypharmacy meant they found organising supplies burdensome.

"And it's not easy enough for me to go to say like phone-in and say just a repeat prescription, I'm on that many and they change them so frequent that it's easier to go down and do it face to face with the doctor" (1.3)

6.2.1.4 Information sharing between HCPs

Patients discussed their perceptions of HCPs sharing information about them and their treatment. Whilst some believed or assumed that HCPs shared information about them, many patients perceived very poor levels of communication between HCPs in their networks. Some made distinctions between sharing information electronically and active communication about them and their health and they perceived cardiac rehabilitation nurses to actively communicate with others, such as hospital doctors and GPs, to make sure they had safe and effective treatment.

"Yesterday she [the cardiac rehabilitation nurse] said that normally a person in my situation would have a particular medication and she mentioned the name, provenil… provenol, something like that, and she was a little surprised that I weren't on it and she said she was literally going to contact the doctor to ask why not because she said there may be a valid reason but she needs to know." (1.9)

Others, however, were frustrated by a perceived lack of active communication between members of their healthcare team, for example between their GP and their community pharmacist or between their GP and hospital staff. Some described their belief that communication sent to GP surgeries was not acted upon, rather it was filed and only read when they next visited the surgery.

"Well I think the nurses and the specialist, the doctor, it's just a washout, my doctor, because he don't seem to be reading the emails what the doctors have sent from the hospital. They just don't communicate, to be honest." (2.17)

"It's all done by letter and I don't think they [the GPs] look at them, to be truthful. I think they get given to the receptionist. She probably puts them on the computer and that's left at that. Because you can go in and they'll say "Well let me have a look. When were that diagnosed? Oh, yes you have." So they aren't aware of what you've got until they actually… I don't think the GPs look at anything that comes through until it's needed." (1.27)

Community pharmacists were judged by some to be isolated from other HCPs involved in patient care because of their limited access to information about the patient, such as their medical record or discharge summary, or because they did not work with other HPCs.

"I mean the pharmacists are an entity on their own aren't they? They don't coordinate with anybody." (1.34)

"I don't think I'd be confident enough [to ask a pharmacist a question] because they've no information have they?" (2-26)

6.2.2 Attitudes and experiences

This section describes how patients and their network members shared their experiences of taking medicines and also how they expressed different attitudes about their medicines within their networks. These attitudes were instrumental (concerned with the cognitive assessment of the value of their medicines) and affective (concerned with how patients feel emotionally about them). Attitudes were often exchanged in conversations about medicines with friends and family network members.

6.2.2.1 Sharing experiences

Patients described how they shared personal experiences of their medicines with friends and family members. They chose to share experiences of medicines with contacts, either because they trusted them or because they had experience with the same medicines or the same conditions or medicines.

"I tell her [my mother] what happened at the hospital and tell her what medication I was on. Again, she's had two or three similar medications so she said, "Alright, well, I take this as well." It was just a general discussion." (2.50)

Patients described discussing the range of medicines they took for similar conditions and how effective they perceived those medicines to be. They described talking about long-term, new, and changed medicines. Network members shared experiences with medicines sometimes led patients' contacts to question the future of their own treatment.

"It was the Bisoprolol because me and my dad both have the irregular heartbeat and we've both been on Atenolol for, well him for about 20 years and me for 10 years…So because they changed my medication he wondered why and whether they would change his." (1.2)

Patients told their friends and family how they were coping with their discharge medicines. They shared how they felt about their medicines and sometimes expressed the burden of having to take too many medicines. Others talked about the different doses they were taking and conversations sometimes led to patients wondering why they were taking different doses to their contacts.

"Well mainly [we talk about] well I'm taking so what's such and such a dosage, well I wonder why you're not taking that dosage while you're taking this and (laugh)." (2.29)

Network members' second-hand experiences were also shared. In one case, for example, the patients' friend shared her experience of her father's warfarin use. Other patients and their network members shared experiences of side effects, sometimes reassuring each other and sometimes intimating that experiencing side effects was to be expected.

"It was just that he'd [her father] been on it [warfarin] and he's fine because she was doing that, "I feel compelled to reassure you that you're going to be okay." (1.2)

"I mean the reason why I know about the beta-blockers is because my mum and dad have told me that they will tire you. Because my dad was on beta-blockers and he was that lethargic, couldn't do anything and you know he always likes pottering in garden but he couldn't do anything." (2.30)

"Oh, they [my family members] just said, "How are you going on?" and sort of thing like that." (1.1)

6.2.2.2 Instrumental attitudes

Patients described developing instrumental attitudes – for example they changed their cognitive assessment of their medicines – as a result of contact with network members. HCPs and support staff communicated the importance of medicines and in doing so reinforced more positive instrumental attitudes in patients. Contact with these network members reinforced how essential it is for patients' to follow their prescribed medicines regimes. For example, a conversation with a pacemaker technician emphasised the importance of maintaining the correct dose of a beta-blocker. In another case, contact with a gym instructor during cardiac rehabilitation led a patient to understand the need to keep her GTN spray with her at all times. This enhanced her view of how important the GTN spray was to managing her condition.

"And then he [the gym instructor] said, 'Where's your GTN spray?' And I said, 'It's in my handbag in the changing room.' And he just said, 'What good is it in your handbag!' And I felt like a little girl….Well I know it sounds so childish, I've got to have that spray with me, I do take it with me, it's in my handbag, but now… the following day I took it with me and I won't ever not have it with me in the gym again." (2.27)

Friends and family contacts also enhanced patients' positive instrumental attitudes. For example, they stressed how important it is for patients' health to adhere to their medicines or emphasised the importance of remembering to take medicines through regular reminders.

"Yeah, we [me and my daughter] talk about the medicines and everything, and she says like if you've got to be on them, you've got to be on them Dad, you know, it's simple. You know, if you stop taking them, something drastic could happen." (2.12)

Indeed, several patients discussed how their personal contacts encouraged them to take their medicines seriously, thus influencing their views of how important their medicines were. Others discussed how they felt a personal responsibility to their family to take their medicines and keep themselves well.

"She [my wife] makes me take them [my medicines] seriously. My problem is if I was more focussed with work, everything else would just get left" (2.35)

"I don't mind [being reminded by my wife], I don't mind at all because it also gives her peace of mind that I am doing it properly now, and that I am following all the stages that I should follow…because you know she cares and alright we've been married 30 years now, you know and she does care about me, and it makes me feel like she still cares and I should take more care of myself." (2.4)

6.2.2.3 Affective attitudes

Patients developed affective attitudes – such as their acceptance, anxiety or fears – about their medicines from their healthcare network members. In some cases they helped patients feel more content about taking their medicines.

"Yeah, I feel better [about my medicines], the more that people tell me [about them]…" (2.17)

However, occasionally contact with HCPs would increase patients' concerns. For example, a community pharmacist who telephoned the patient to check whether they were experiencing any side effects enhanced the patient's worry about her medicines.

"Oh it's scary, I think why are they doing this [phoning me], what's going to happen? And sometimes I think well, I might be having… because sometimes my head feels like it's going to explode and I think perhaps that's a side effect." (2.22)

Friends and family raised concerns about medicines, which led patients to worry about those medicines or take action, such as querying their medicines with a HCP. One patient reported his wife's concern about the number of medicines he took which amounted to nine tablets a day and seven different medicines. A different patient's daughter highlighted the number of medicines he took with a blood-thinning effect and the negative impact this might have. This in turn made the patient concerned and he approached his community pharmacist and his GP surgery about them. In this case, the community pharmacist advised him to stop taking one of his medicines, but staff at the local health centre later indicated that the community pharmacist did not have the authority to do this.

"Well it was my daughter; she said…my daughter looked at my pills. She said, "You're taking three lots of blood thinning tablets and they're putting you on warfarin". She said, "What are they trying to do to you?" So I went into the health centre and I told her. Before that I went to the chemist and told her. The chemist woman said, "Well don't take your aspirin and don't take another one". So when I went to the health centre… I must have said to her the chemist said I'm to stop taking my aspirin and I have to stop taking this". She said, "She's not allowed to do that" (2.15)

6.2.4 Offers and requests

This theme describes how patients would make requests for repeat medicines and also for medicines that were missing from their prescriptions or delivered medicines after their hospital discharge. It also describes how they would request and be offered help with their medicines.

6.2.4.1 Requests for medicines

Some patients described requesting prescriptions from their GP practice after their discharge. They did this via the GP receptionist and saw it as a basic part of the receptionist's role, which some patients valued more than others.

"I don't think they [the receptionist] really helped me have they? Just you go and ask for your prescription and they give it you." (2.26)

"She [the receptionist] was very confident, clearly spoken, asked me questions, a lot of the time they just mumble and go 'what do you want?'. She

was very, what was she, she was proactive, she was interested in what, what I wanted to know and interested in sorting it out." (2.35)

A few patients described how they had needed to request specific medicines that they noticed weren't on their repeat prescriptions after they had checked.

"No, they [the new medicines] weren't [on my prescription], I had to ask for those; they are on now and they will be next time." (2.52)

6.2.4.2 Requests and offers of help

Some patients described how they needed help with their medicines when they returned home from hospital. They described how they turned to others in their personal networks to provide that help. One patient described how she had felt incapable of undertaking the organisation tasks she felt she needed to begin taking her discharge medicines so she requested help from her husband.

"When I first came out I wasn't feeling very well. My brain to concentrate was not, it was fuzzy and normally, I was going to put all the tablets and the times I should take them etc. on a spreadsheet and I asked him [my husband] if he'd do that for me because I was feeling a bit fuzzy." (2.34)

For most patients help seemed to be offered implicitly by their friends and family without patients describing needing to ask for it. Some patients described the reassurance they got from knowing that they could ask for help from their friends and family should they need it.

"You know it is a fair way [away] but they're very good [my friends]; if I asked them to do anything they would." (2.1)

Other patients described how they felt they could ask certain HCPs for help should they need to do so, for example they described confidence in how they could ask their cardiac rehabilitation nurse for anything at any time.

"I feel, even when this is all over, well I suppose it is now, I feel that if I was apprehensive about anything to do with my tablets I think it would be [the cardiac rehabilitation nurse] that I would ring to ask because she's so easy to talk to." (1.17)

Offers of help came from healthcare staff, for example one community pharmacy staff member offered to drop medicines off at a patients home after she discovered the patient had run out of supplies. Others offered practical assistance, for example in writing the names of medicines down for patients or in banding medicines boxes together for them.

"[She] said, "You've none?" I said, "Well I've one," or I'd ran out the previous day, and she said, "Well I can't have you run out, I'll bring them on my way home from work." (2.17)

Whilst help from family was often described by patients as being implicitly offered, there were instances where patients described family members explicitly offering help, for example with collecting medicines from the community pharmacy.

"He [my brother-in-law] has got all my medicine for me and then when I needed to get it he said 'don't be doing that, I'll do that'. (1.47)

6.3 Ego-network function

This section explores the functions provided by patients' medicines management ego-networks. It is presented in four thematic areas and in 11 subthemes, as shown in Figure 45.

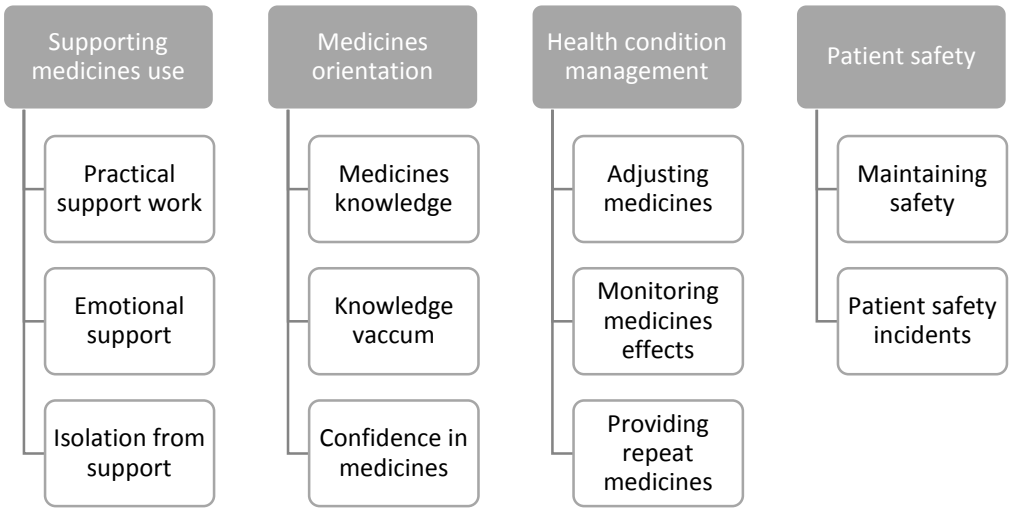

Figure 45: Thematic map of the function of patients' medicines management networks

Patients' networks were identified as multiplex because they provided different types of function. For example, they offered support as well as supplying medicines. The main thematic areas are: health condition management; medicines use support; medicines orientation; and patient safety.

6.3.1 Medicines use support

The theme of medicines use support is presented in three subthemes: practical support work; emotional support; and isolation from support.

6.3.1.1 Practical support work

Patients reported personal network members giving them day-to-day practical support in managing and organising their discharge medicines. Family members set out tablet boxes for them each day or organised each week's supply into multi-compartment boxes. For many this support was invaluable, particularly because they felt themselves unable to perform these functions because they didn't have the skills or because they were tired, disorientated or unwell. Some patients described working as a team with a close contact, such as a spouse, to obtain and organise supplies and to take the correct medicines at the recommended time.

"She [my wife] does my tablets because they're little, some of them are little tablets and that and I find them… so it's easier if I just stand there and say they're for morning and they're for evening and she'll put them in my dosette box and that." (1.3)

Others described needing practical support from close family members immediately after discharge from hospital to help establish an in-home medicines system. This help comprised making appointments to discuss medicines, organising medicines or in buying compliance aids, such as multi-compartment boxes.

"So she [the cardiac rehabilitation nurse] took my blood pressure sat down, stood up, sat down, stood up… like they do, and she says, 'are you having any problems with your medicine?' I said 'no, none at all', I said 'daughter got me one of those things [a dosette box], so it's all laid out, so I do a week at a time'. (1.34)

"Well, my husband did it [organised my medicines]. He'd bring me them all at first. Yeah, then he had to go back to work after a week. He used to bring all the tablets out to me." (1.27)

Other patients talked about getting support collecting medicines from the community pharmacy or getting lifts to the pharmacy. This was described as useful by patients who were either too ill after leaving hospital to collect their medicines themselves or were temporarily precluded from driving because of their health. Some patients discussed how they relied completely on their spouses to manage medicines at home on their behalf.

"Well it's the organising, [my wife] does everything. If she left tomorrow or dropped dead tomorrow then that'd be it; I'd go cut my throat then; no seriously but I would be totally lost for a while to sort out..." (2.11)

Some were able to create their own lists in note books or on spread sheets to help them keep track of what they had been taking. Others used different tools, such as alarms to remind them to take doses they had forgotten, or strategies such as placing their medicines in easy view so they would not forget to take them. Some described their difficulties keeping track of their doses. Further medicines help would have been beneficial for some and they made suggestions about the types of help they might have benefitted from, for example some described how a checklist or organisation tool might help them take their medicines correctly and establish a routine.

"I think if they sent you out of hospital with some sort of tick box sheet you know, I think it would have helped a lot of people, just so that, I mean like, I have to keep them there to remind me and my alarm is set on my watch for 7:00pm every night because the first two are okay with breakfast because it's become a habit, but the evening one, sometimes I forget so I have to set my alarm and I mean there was a time in the past where I thought, did I take one, and I had to count them all, to see if I'd taken one you know, and I think if there was some sort of simple check box or something that you could just keep next to you, you know or whatever." (2.34)

6.3.1.2 Emotional support

Actors in patient' personal networks offered emotional support enabling them to continue their treatment. The fillip provided by people who cared about them helped patients recover when they were physically and emotionally depleted, as indicated by the exchange below:

F "They [my parents] always ask me every day if I've took me tablets. But always you know I always have. And he'll come 'have you took your tablets?' Yes."

I: And how does that make you feel having that reminder every day from your parents?

F: It's actually good at the moment because at the moment I can't think straight, I'm a bit, I get very tired. And it's good to have somebody just reminding me that I've got to take it even though I am taking it. (2.20)

Patients felt cared for by their personal contacts whom they described as being available to discuss the emotional impact of taking medicines. They described this type of support as valuable, particularly when friends and family lived close to them or with them and provided regular or constant support.

*"She [my daughter] is at home and she all the time she takes care of me…so it's the support you need you know, sometimes." (*1.11)

"Because I see her every day and basically she makes me take my medication and says, 'Are you alright? Are you really alright? If you're lying to me...' (1-2)

Emotional support functioned in different ways. Personal contacts provided day-to-day encouragement, either through nudging patients to take their medicines or through listening or discussing concerns about medicines. Some explained how close personal contacts would reassure them that they were taking the correct medicines. These contacts were usually people who had medical training themselves, for example one patient described how his wife who is a nurse would reassure him that his treatment was suitable for him.

"It gives me reassurance if she says oh you're on right treatment, you're on right drugs then yeah, so that and all that drugs that's it, you know there's nothing to worry about from that side of it so." (2.21)

Close contacts provided support in making decisions about their medicines, such as whether to adjust doses, carry on taking them or to stop taking them altogether. For example, one patient in conjunction with his wife decided to stop taking ranolazine because of the chest pains he experienced, which were eventually attributed to his need for a proton pump inhibitor.

"The conversation as to whether to take the extra medication was pretty much mine, but after I'd talked with [my wife] about it." (1.8)

6.3.1.3 Isolation from support

Some patients described their isolation from both emotional and practical support with their medicines upon leaving hospital. Some patients lived alone and perceived that they were managing their medicines single-handedly. Others talked about their fears for their health after leaving hospital which were exacerbated by their isolation.

"It's difficult really, I think anxiety, see what I fear is that I'm on my own and at night time you know they're not sure whether it's a phase I went through before Christmas when I never slept for four or five days because I was frightened of closing my eyes…" (2.1)

Others felt let down and uncared for by the GP team, disillusioned with the care they experienced and some perceived a breakdown in their relationship with their GP and consequently had not tried to access their support. Some patients described how disorientating it is to leave hospital where they were surrounded by members of the medical team and then return home to comparative isolation. They explained how this could make them feel insecure and they perceived the need for access to support after their discharge from hospital.

"Well whilst you're in hospital you're very secure, when you leave hospital it's incredible how you feel insecure initially because you've got that full back up there in hospital. The moment you come out of hospital you're on your own and it is important to have somebody there to...or at the end of a phone that you can ring up." (1.52)

Some patients perceived a need for a greater role for healthcare professionals in providing support after discharge. They were frustrated at the lack of continuity in their care team and particularly perceived poor continuity in their

contact with a GP. These patients perceived a burden in updating HCP members about their health condition or of having to wait to see their GP of choice.

"I think you should be able to see the same doctor all the time, because you keep telling the other doctor, you know, everything, and they don't… you can't read it up. (1.25)

"I think above anything would be a form of contact with someone that knew about it, not possibly personally but about heart attacks, you know, it doesn't happen as much now but in early days there were a lot going on that I want answer to and there were nowhere to go for them." (2.26)

6.3.2 Medicines orientation

The theme of medicines orientation describes the process through which patients do and do not learn about their medicines and develop different levels of confidence in using them. The term was coined as a result of this analysis to capture the idea of how patients reach preparedness to manage their medicines and it is discussed in depth in section 8.7. It is presented in three sub-themes: medicines knowledge; knowledge vacuum; and confidence in medicines.

6.3.2.1 Medicines knowledge

Professional network members performed overlapping education functions: some patients had contact with several different professionals to find out about their medicines, their purpose and how to take them. However, cardiac rehabilitation nurses played a valued role for patients in educating them about their medicines.

"Yeah, well he did say, he told me that is how, this is for your stent, that is the one he mentioned. He goes that is for your full year which [you] need your body to, you know, recognise in to it." (1.10)

They were perceived as being experts and patients described how they would fully answer medicines questions. Patients appreciated the easily understandable language that cardiac rehabilitation nurses used to teach them about their medicines and they were able to recall what they had been taught during visits. Cardiac rehabilitation nurses often visited patients at home and

patients reported how cardiac rehabilitation nurses appeared to have time for them.

"Any questions I had to ask her [the cardiac rehabilitation nurse] she answered straight away and she knew. I think she must... she'd been doing it a fair while I think so she definitely was on the cardiac wavelength, if you will so yeah, she were fine." (2.10)

Pharmacists also educated patients about their medicines: a few patients described pharmacists conducting medicines use reviews which helped them understand more about their medicines. Pharmacists were able to help patients allay side effects and optimise their medicines through making recommendations about when to take them. Some patients, however, were confused about the purpose of their review, thinking it was perhaps for the benefit of the pharmacist rather than for their benefit, or they thought that it did not give them any additional knowledge, or they were unprepared for their review because it was conducted in an ad-hoc way.

"But the other thing is that if I'd been prepared to go in and knew that she [the pharmacist] was going to talk to me but she literally took me off…" (1.40)

Other patients felt strongly that GPs or other doctors should provide education about their medicines, rather than other HCPs, such as pharmacists, because they thought the responsibility of educating the patient should sit with the prescriber.

"In my mind I was going to say they're the people that put me on it in the first instance, they're the people that said this is the drug you've got to take. The pharmacist dispenses what the doctor says so he can go through what he dispenses but the person who actually puts me on them, he should be telling me or she should be telling me the reasons why I'm on it not the other way round." (2.52)

6.3.2.2 Knowledge vacuum

At times patients explained how they were frustrated by their lack of knowledge of their medicines. They explained that poor provision of patient information resulted in poor medicines understanding. Patients talked about how they had

left hospital without a good understanding of their medicines and some felt hat they had continued to be ill-informed despite contact with others in the six-week period following their discharge.

"But it's galling when, you know, like you say, I'm coming out of hospital with some new tablets and all I know is to take them twice a day – well what are they for?" (1.3)

"But I don't know why I'm on water tablets. I couldn't tell you why I'm on water tablets. Nobody's explained that to me. I mean I know what they do, they just flush out don't they but nobody's actually explained what the water tablets do." (1.20)

Patients were confused about many aspects of their medicines, including changes made in hospital, the explanations they were or were not given in hospital, changes to brands of medicines and about side effects they perceived. Patients also lacked the ability to tell if their medicines were effective for them personally or how they worked together to help their health condition. They described making guesses about the effects they should expect.

"If I had to make a list of everything that I feel at the moment, yeah I would, I would like to go down and say right "is this because of this, is this because of the drugs I'm taking, is it part of the symptoms that I'm having"?...Because my, thyroid because I'm so high and the beta-blockers are slowing me down. So is my thyroid slowing, they did say it would slow me down. But is it the thyroid or my heart that I'm having these symptoms for? And if so will they change my tablets accordingly or would they you know take me off one or reduce the dosage?"

Other patients admitted that they had limited understanding of their medicines, but they were aware that they could find information if they wanted it.

"The information is there in packets but I couldn't say I knew what they were for now." (2.26)

6.3.2.4 Confidence in medicines

Patients described different levels of confidence in their medicines. Many explained that they felt little need to be comprehensively educated about their

medicines because they had high levels of trust in the medical team or trust in their medicines. They discussed how this confidence had been engendered though their contact with others in their network, such as their cardiac rehabilitation nurse. Others had confidence in their medicines because of their trust in their GP or the hospital doctor who prescribed them.

"I trust whatever is given to me. You know if they say it's going to make you better then I just assume that the doctors or nurses or whoever are telling me the right thing and I will go with that. I've never felt unsafe taking anything." (1.20)

Patients' confidence in their medicines was undermined if they read about or experienced side effects that they were not expecting or were more severe than they had expected.

"I just think you can feel a bit off with that one and I've got asthma as well and I know when I've read the... that one's really quite bad to give with asthma. They say because it's a beta-blocker and it says warning that it can cause a lot more problems with your breathing and everything else but they've not questioned that, they've just given me it, so." (1.27)

Some patients considered the impact of stopping their medicines and other discontinued medicines they perceived to be making them feel unwell. Others experimented with adjusting their doses to allay perceived side effects. Some patients described how being in receipt of more information about their medicines would help increase their confidence in their medicines.

"And it does give you a confidence in taking the tablets they've given you, because you know exactly what they are, exactly what they're going to do, you know. So it does give you that bit more confidence, rather than just taking them". (2.12)

6.3.3 Health condition management

Patients' professional contacts optimised their medicines to manage patients' health conditions. They did this through monitoring patients clinically, adjusting doses and changing medicines and providing medicines to patients.

6.3.3.1 Adjusting medicines

Warfarin nurses adjusted doses and monitored patients' INR levels in response to the prescribed dose and other lifestyle choices. GPs and hospital doctors would increase or decrease doses in response to test results or to instructions from other HCPs, such as hospital doctors. A few patients had attended hospital again as emergency patients and had their doses re-adjusted by the hospital. Patients also reported heart failure nurses adding medicines and adjusting their doses of medicines, such as Furosemide, which is used to treat fluid retention in heart failure.

"Prednisolone yes, that's because prior to going in hospital the decision had been taken by the doctor that gave me that at [the clinic] that we were going to gradually reduce it and she said she'd [the GP] received the letters from him and she would take over that, managing that reduction." (1.9)

In a few cases, in an MUR community pharmacists would explain how medicines could be changed to work more effectively for the patient or how patients could modify how they took their medicines to effect more optimal outcomes, for example by taking medicines at different times of the day to get more effective outcomes.

"What we were doing, we were taking them at night, weren't we? She [the community pharmacist] said "No", she said "take them in the morning, you're all right, you can take them any time". So that's Ramipril and one of them at night, then take some of them in the morning as well." (1.40)

Others discussed how GPs would amend medicines and doses in the period after leaving hospital, sometimes driven by others in the network, such as cardiac rehabilitation nurses and sometimes due to the patient's concerns about side effects.

6.3.3.2 Monitoring

Patients saw several professionals who monitored their treatment. For example, GP practice nurses, specialist nurses and doctors would monitor patients' responses to their medicines by ordering and conducting tests and reviewing results. Patients would attend clinic appointments with diabetes specialist, COPD nurses and warfarin nurses, whilst cardiac rehabilitation nurses and

heart failure nurses would often visit patients and examine them at home. In one case a cardiac rehabilitation nurse had asked a patient to keep a diary of the pain he was experiencing so she could advise about his use of paracetamol and GTN spray.

Professionals played complementary and overlapping roles, for example GPs replaced, adjusted and added new medicines sometimes in response to patients' concerns about side effects or because they identified interactions. Cardiac rehabilitation nurses monitored and adjusted medicines, and GP practice nurses monitored patients' medicines. In one case a community pharmacist telephoned a patient twice to monitor his response to an increased dose of Ramipril.

Patients described how cardiac rehabilitation nurses were effective in managing their medicines to better manage their health condition. They saw these specialist nurses as embedded into the healthcare team, working with other HCPs to optimise their treatment. They described them actively checking the suitability of medicines, substituting medicines that patients were experiencing problems with, monitoring and communicating the titration of doses, and advising the introduction of medicines that they thought patients should be taking.

"She [the cardiac rehabilitation nurse] takes my concern and she's the one who has been talking to the doctor. She's communicating with him and getting things done. She came round Tuesday this week and then a couple of days later Dr [doctor's name] rang me up to say "Right. I want to up the dose of Bisoprolol to 10.5 mg." (1.45)

"Yes, [the cardiac rehabilitation nurse], she said she'd got some results from a blood test that I had at my doctors…and apparently the test is okay but this is for the function of the kidneys. So long as it wasn't affecting the function of my kidneys too much I was on two and a half milligrams, now they've put me up to five. The aim, I believe, is to get up to ten. That would be the ideal dosage to work at the best but they're monitoring and putting it up slowly. At the moment I'm taking 5mg as opposed to just 2.5 of Ramipril." (1.51)

One patient reported that the cardiac rehabilitation nurse had noticed he should be taking isosorbide mononitrate approximately one month after his discharge.

The patient subsequently talked about his disappointment that his recovery had been hindered because it had not been prescribed to him at discharge.

"To be totally honest with you I felt really let down…I should have been on these [isosorbide mononitrate tablets]…I thought hang on a minute... Why has that happened, you know why, I've been suffering for another four weeks, because it was every single day I was having an angina attack, every single day. I mean within sort of five minutes of meeting the cardiac rehabilitation nurse she had it all sorted out." (2.14)

GPs also played a role in monitoring medicines, although many patients reported problems getting appointments with their GP. However, some patients found it difficult to access the monitoring functions of their GP once they left hospital, which left them to self-monitor their health.

"That was when I left hospital they said they were discharging me into the care of my GP, and I had to make an appointment to see him when I got out, because they needed him to regular monitor my blood pressure. So the day after I got out, I rang them up and the first appointment they could give me was three weeks, but fortunately I had a blood pressure monitor in the cupboard, I just needed to replace the battery, and for the first few weeks I was taking my blood pressure two or three times a day." (2.34)

Often patients perceived a lack of co-ordination in the system in optimising their medicines. They talked about a lack of communication and co-ordination about them and their treatment between HCPs

"I mean, like there should be somebody watching each other, you know like there is a boss, let's say my boss is going to be my Mrs, she is going to keep an eye on me whether I'm going to be looking after my health or not. So she is the one who is giving medicine, tells me what to do, what not to do and they should be into doctor wise and even with the pharmacy or doctors, anything, they should communicate with each other." (1.10)

6.3.3.3 Providing repeat and new medicines

Patients described how professional network members would co-ordinate supplies of their medicines. They described GPs authorising prescriptions, GP receptionists acting in an administrative role in taking down notes of patients'

medicines and organising repeat medicines, and pharmacists dispensing those medicines to patients.

"I came out of hospital on the Friday, the Monday I went to see the GP, and said look this is what they've done, because I took the letter with me, the discharge letter…and he said 'right, so we'll just order you know these to go onto repeat, do you need anything else?' I said no. I said I've got a month's supply, I'd just got a new supply and so I just carried on. He says you know what to do." (2.4)

Some patients described community pharmacy playing an important role in managing the organisation of their supplies. Pharmacy delivery drivers delivering to their homes and pharmacy counter assistants coordinated and supplied patients' repeat medicines and they often precluded the patients' need to have direct contact with a pharmacist in order to obtain their medicines. One or two patients reported how their community pharmacists had contacted their GP on their behalf to solve problems with the supply of medicines. Others patients reported problems with their supply of medicine, for example medicines being delivered in stages rather than all at once by their pharmacy. One patient reported that the pharmacist supplied 100mcg tablets of Thyroxine on one day and 50mcg tablets a few days later to make up her prescribed dose of 150mcg.

6.3.4 Patient safety

During interviews patients described the safe management of their medicines but also medicines related errors that might potentially have caused them harm. The theme of patient safety is presented below in two sub-themes: *maintaining safety*; and *patient safety incidents*. In total 31 incidents described by patients were reviewed by two clinicians (See Appendix 6) and 16 were classified as being patient safety incidents.

6.3.4.1 Maintaining safety

Many patients perceived the system of providing them with medicines as working safely and efficiently. Community pharmacists provided a safety-net for some patients. For example, in some cases patients described the community pharmacist checking with their GP that a medicine was suitable.

"So he took me into his little room at the side of the pharmacy and he said well he said I don't think you should be taking this; he said I'm going to ring the doctor. So he rang the doctor, and checked on it, that I should be taking this pill and then he rang back. He said I've had a word with the doctor; yes, he said it's all right." (1.4)

Other patients described community pharmacy helping them by providing emergency supplies of medicines or taking the time to thoroughly check medicines. Some described how they valued the important role the community pharmacist plays in providing medicines that are safe.

"They are very thorough [the pharmacists], they seem to be… They take their time, don't they, going through it all and checking it all." (1-27)

"Like the chemist for instance I don't know the chemist…he checks that I've got the right tablets so he's very important." (2-13)

For many patients the systems they accessed to obtain repeat medicines after they left hospital worked efficiently. They described how the changes made to their medicines in hospital had been maintained when they had been supplied new medicines.

"No I haven't had to do anything to anybody [to get my repeats medicines], I haven't had to say anything to anybody, whether they've all be on you know, they're on top of their jobs actually." (2.8)

One patient also perceived her medicines use review with a pharmacist as a valuable safety check ensuring that her medicines would not cause her any harm.

"Well in effect [the review] made me feel a lot better that you know they were checking them and you know if I was... I wouldn't be taking an overdose, you know that you know they…keeping them in check." (1-4)

6.3.4.2 Patient safety incidents

Several patients reported instances in which they were unable to obtain repeat medicines after their discharge from hospital. They described trying to order their medicines from their GP practice to find that discharge information detailing their discharge medicines was not available on the GP practice

system. In some cases the paperwork was soon located yet in others the patient was asked to list their medicines for the practice or to provide a copy of their hospital discharge letter. One patient found that upon asking for a repeat prescription, information about his new medicines from the hospital was not available. The receptionist at his GP surgery photocopied the discharge summary, but only the first page of it so some of his repeat medicines were missed. In the process of rectifying this, the GP surgery issued two duplicate prescriptions to the pharmacist. Another patient received a set of medicines without nicorandil, which had been prescribed by the hospital. This occurred one week after his discharge when his wife handed in his repeat medicines request slip at the GP surgery. A further patient received duplicate sets of medicines from two different pharmacies, which she described as being stressful. Some patients reported repeat medicines supplies being delivered without items that were new or had been changed in hospital and patients needed to intervene to resolves these errors.

"But apparently they couldn't find that one at the doctors. So when my tablets were due to be renewed, my prescription, they didn't know anything about it. And I were panicking a bit because I thought I have no more tablets. So I went… well I had tablets before I went there, so they were due as well, and when they came and they said, you know, they'll be ready on Wednesday. My husband went to pick them up and when he came back, I said 'Where are my new tablets?' So I rang and she said well, we haven't been able to find this note from the hospital. I said but, when I rang about them, she told me to give her the list that was on my list and I did. I gave her the list and what the tablets were. She said, 'Right, don't worry, it'll be ready for you,' and nothing was." (2.22)

One or two patients described receiving incorrect medicines during this post-discharge period. For example, one 80-year-old patient explained how she was supplied uncoated rather than coated aspirin by her GP. She explained that uncoated aspirin made her sick and dizzy and she suspected that the GP had not read the notes from the hospital. She was frustrated by this, explaining that *"there's enough wrong me, without being sick on top"* (2.25). Others described events during the period following their discharge that might have resulted in harm which were caused by poor communication between HCPs and patients. Patients described being upset and frustrated by what had happened to them

and sometimes they experienced adverse effects. One patient, for example, had been supplied repeat medicines with different brand names and different shaped and sized packaging to his discharge medicines. When he saw the boxes he assumed his GP had prescribed these medicines in addition to those given to him in hospital. He proceeded to take double the dose of at least three cardiology medicines used to treat high blood pressure and angina. He described becoming disorientated, nauseous and believes he lost consciousness for about ten minutes.

Another patient was prescribed 50mg of flecainide twice a day by the hospital. His GP then prescribed 100mg tablets, however the patient didn't notice the change, which was not actively communicated to him, and he continued taking one pill twice a day, effectively taking twice the dose for approximately three weeks. He explained that someone should have communicated the change of dose to him:

"If I'd been ill I would have been a bit cross I suppose, probably with myself and the pharmacist, which possibly should have said you know these are 100 just, you'll need to take half." (2.33)

He communicated what had happened to his GP surgery and was surprised when he heard nothing in response.

"It's sort of, I asked, told the receptionist what had happened…so she told the doctor and I went to pick the new prescription up. There was no comment from the doctor. I asked her…so I said, 'Has he said anything?' She looked on the computer and said, 'No he just wrote the prescription', a new prescription out, so I went and got those." (2.33)

6.4 Discussion

This chapter has provided a rich interpretation of the content and function of patients' medicines management ego-networks in the six weeks following their discharge from cardiology wards. The content in patients' ego-networks comprised information and advice about medicines from both professional and lay sources. Many patients described leaving hospital with insufficient information about their medicines and their networks acted to fill some of those gaps. Patients also described instances when they had provided information to

HCPs about the medicines they needed and at times their perceptions of the effectiveness of information sharing among professionals in their networks was poor. Patients' cognitive and emotional attitudes about their medicines were also influenced by their personal and professional contacts, they described requesting medicines supplies and asking for and being offered help by their network members. Patients' medicines management networks were multi-functional: they provided medicines orientation, practical and emotional support as well as health condition management through the supply, adjusting and monitoring of medicines. It is also clear that patients' networks pose risks to their safety through the failure of systems that support medicines management and through failing to ensure patients fully understand the changes that have been made to their medicines.

Patients' professional network members provided health condition management functions, such as providing, amending and monitoring medicines. Medicines orientation – the process of developing an understanding of and confidence in their medicines – was offered by different HCPs and was duplicated for some patients. Some patients had no contact with these functions which resulted in a knowledge vacuum: they reported having unanswered questions about their medicines and in some cases they considered stopping or actually stopped taking them. Despite multiple HCP involvement in their medicines, approximately a quarter of patients experienced safety incidents yet the extent to which the patient safety incidents identified were officially reported remains unclear. In many cases HCPs were made aware of the incidents – for example one patient had asked if the GP had commented about his incorrect flecainide tablet size and was told that the GP had not left any comments. Patients who failed to be prescribed the correct medicines after discharge, or could not obtain their prescription because the hospital discharge information had not been processed, did not report logging complaints. Patients and practice staff needed to take action to ensure the correct medicines were supplied, yet it is likely that neither the GP practice nor the patient officially registered these as patient safety incidents. The overall level of reporting of safety incidents in primary care is thought to be comparatively low.[72,76] To counter this in 2015 NRLS launched a primary care safety incident e-report form to make it easier for GP practices to report incidents for which they can gain continuous professional development

credits;[344] and the recently launched NICE guidelines on medicines optimisation recommends that robust processes to report safety incidents are now implemented.[72] In secondary care patients have reported, when solicited, safety incidents in a range of categories including their medicines.[33] As yet, there is no evidence about patient reporting of incidents in primary care, although NICE now recommends that HCPs tell patients, their families and carers how to identify and report medicines-related patient safety incidents.[72] Reporting of safety incidents is discussed in more detail in the general discussion in section 8.6.

As in previous research, for these patients the systems supplying repeat medicines after hospital discharge caused problems.[150,164,166] This resulted in patients intervening to co-ordinate the supply of information to obtain their medicines and to avoid taking incorrect medicines. That patients can identify and offer information to rectify errors is evidence of increased system resilience because patients adapt and take action to enable error recovery; however some patients would probably be unaware that their prescriptions were incorrect and therefore not able to take action to ensure they received the correct medicines. Other patients have experienced problems and discrepancies with their medicines after discharge;[125,126] yet those studies did not include the problems patients had in obtaining their prescriptions before the issues were identified, instead focussing on problems identified once prescriptions had been taken to the community pharmacy.

A quarter of the sample had no direct contact with their GP after leaving hospital and some patients were disappointed in what they perceived to be their GP's lack of interest in them and their recent health crisis. Fewer had direct contact with a community pharmacist. Implementing a pathway for accessing professional medicines support following discharge from hospital which is personalised to the patient and communicated clearly to them would help orientate patients and would ensure medicines information came from the most relevant professional group, for example should they be on a cardiac rehabilitation programme then medicines orientation is offered by the cardiac rehabilitation nurse; should new medicines be supplied to other patients then a different pathway should be integrated. NICE recently recommended that organisations consider home visits or telephone follow up for some groups of

patients after discharge, including those taking multiple medicines and with chronic conditions to provide additional support for some groups of people.[72] This research demonstrates how valuable patients perceived the input of cardiac rehabilitation nurses and heart failure nurses providing personalised support to patients in the home, however not all patients are eligible for that level of service.

The MUR in the UK directs patients to community pharmacy to provide additional support with their medicines.[345] Although few patients in this study had participated in an MUR, our findings suggest that as it is currently designed and implemented the MUR may not demonstrate value to patients. This view is shared by patients in previous research which found that whilst the MUR reassured patients that they were taking their medicines correctly, it could better meet patients' medicines use support needs including discussing any complicated concerns patients may have about their medicines.[116] Some patients did not visit a community pharmacy in person because a relative or friend went on their behalf or because they used the delivery service offered by a community pharmacy. This limited their opportunity to be approached by a community pharmacist to review their medicines. Other patients described experiencing an MUR but had not been able to prepare for it because it had been conducted straight away, or that they had been unaware of or misunderstood the purpose of the MUR. Observation research has found the MUR to lack breadth of discussion and that the work environment and workload prevented pharmacists from offering a more meaningful service to patients.[346] Patients in this research were not always aware of the purpose of the MUR or for whose benefit it was being conducted; in other research MURs were presented to patients as a quick medicines check and patients were unable to set their own agenda for the consultation.[346] Community pharmacists have been found to recognise the benefits of the service, although they perceived barriers to conducting MURs, including suitable consultation space and resources, and they were concerned about how much GPs value MURs.[347] During MURs community pharmacists have also been found to be reluctant to probe into patients' medical backgrounds or to address sensitive issues.[346]

In this research, contact with others provided the multiple functions that both facilitated and restricted optimal medicines use and risked the safe

management of patients' medicines. Considering the level of involvement in medicines management of other network members, such as spouses, it is clear that interventions aimed at optimising patients' medicines after they leave hospital should take into account their social structure. If patients have devolved some or all of the responsibility for their medicines to others and are influenced by friends and family in how they view their medicines, then interventions aimed solely at the patient will fail to have the intended effect. Indeed, other social networks health studies have identified the extent to which close family members performed illness work and medicines work.[247,257] Psychosocial health interventions involving family members have reported positive outcomes for both patients and families;[348,349] and practical support, family cohesiveness and not living alone have been found to impact on adherence.[256,270] Other patients who are socially isolated should follow an alternative pathway that takes into account the additional help or guidance they might need to manage effectively.

This chapter has described the content and function of patients' medicines management ego-networks. The following section will explore patients' responses to a questionnaire about their experiences with their medicines administered six weeks after their discharge from hospital and how aspects of their ego-networks were associated with their responses.

Chapter 7 – Discharged patients' medicines experiences

7.1 Introduction

This chapter explores patients' responses to the questionnaire administered at the end of their qualitative interview, approximately six weeks after they had left hospital. The aim of the questionnaire was to measure patients' experiences with their discharge medicines. It explores how well the questionnaire items worked to form a reliable scale about patients' medicines experiences and also if there were any robust sub-scales present in the data that could be analysed separately. Exploratory data analysis was conducted to synthesise the ego-network structural data described in Chapter 5 with the questionnaire data. This analysis also incorporates the frequency of safety incidents reported by patients.

Patients were asked to answer a series of nine questionnaire items. Each item asked about an aspect of their experiences managing their discharge medicines, about their understanding of their medicines, their ability to ask questions and get information, or about their perceptions of staff working together to support them in managing their medicines. All 61 patients answered each item. Response options were constructed on a Likert agreement scale and participants were able to select one of five response options: Strongly disagree; Slightly disagree; Not sure; Slightly agree; and Strongly agree. Participants were free to answer in any way they chose. Their responses were given a numerical value from 1 (strongly disagree) to 5 (strongly agree). Questionnaire items were:

- When I left the hospital, I clearly understood the purpose for taking each of my medicines;
- I am confident I can take my medicines as instructed;
- It is easy for me to ask my community pharmacist questions about my medicines;
- When I left the hospital, I clearly understood how to take each of my medicines;
- It is easy for me to understand the instructions I was given for my medicines;
- It is easy for me to ask my GP questions about my medicines;

- I currently understand the purpose for taking each of my medicines;
- The healthcare team work together to support me in managing my medicines;
- It is easy for me to get all the information I need about my medicines.

7.2 Results

The frequencies of patients' responses are shown in Figure 46. In responding to questions patients were overall very positive about their experiences. The majority of patients strongly agreed that they understood how to take their medicines when they left hospital (73.8%) and strongly agreed that they were confident in taking their medicines as instructed (78.7%). Fewer patients strongly agreed that it was easy for them to ask their GP questions about their medicines (45.9%), that it was easy for them to get information about their medicines (55.7%) and that the healthcare team worked together to manage their medicines (26.1%).

Mean values for each question were calculated and are presented in Table 33 by site, gender, deprivation band and for ethnic minority patients, along with patients' overall responses. The lowest mean value overall was for the item 'The healthcare team work together to support me in managing my medicines' with a mean of 3.36, and females responded less positively to this item at both Site 1 with a mean of 2.44, and Site 2 with a mean 2.78. Comparatively low values were reported for the item *'When I left hospital I clearly understood the purpose of taking each of my medicines*' with a mean of 3.72. Males at Site 2 responded the least positively to this question with a mean 3.55, and females at Site 2 the most positively with a mean of 4.33. Patients also gave comparatively less positive responses for the item *'It is easy for me to ask my GP questions about my medicines'* with a mean of 3.75. Females at Site 2 were the least positively about this item with a mean of 2.89. Patients overall tended to report high levels of confidence in their ability to take their medicines as instructed (mean 4.51), that they currently understand the purpose for taking each medicine (mean 4.4), and that it was easy for them to understand the instructions they were given for their medicines (mean 4.31). Patients from areas of medium deprivation responded more positively than those from low and high deprivation areas. Patients from ethnic minorities were overall less positive than others about their confidence to take their medicines as instructed

(mean 3.89 vs 4.41) and less positive about the ease of getting the information they need about their medicines (mean 3.56 vs 4.15). Women at Site 2 were highly positive about their medicines experiences, except for the ease of asking their GP questions about their medicines (mean 2.89) and their perceptions of the healthcare team working together to support them in managing their medicines (mean 2.78).

7.3 Constructing a medicines experience scale

Values for all items were summed to form a scale which measured patients' experiences managing their discharge medicines, thereby yielding a scale value for each participant. A scale reliability test was subsequently undertaken. In the first instance the inter-item correlations were explored to ensure none of the scale items were highly correlated. Correlations are reported in Table 34. The scale was assessed by determining its Cronbach's α scale statistic, which was α = 0.74.[302] A reliability statistic of α > 0.70 is acceptable, thus it was judged the items together formed a reliable scale.[301] A further investigation into whether the scale would be more reliable if any item were deleted was undertaken. The results of this analysis are reported in Table 35.

The item-by item analysis indicated that the scale would be improved if the item *"It is easy for me to ask my community pharmacist questions about my medicines"* were removed. Without this item removed the scale consisted of eight items α = 0.75. This formed a superior scale for analysis following the methods of Field (2009). The Medicines Experience Scale (MES) was thus formed of eight items. It is possible that this question does not capture a meaningful patient perspective on the availability of community pharmacy services, for example respondents may have perceived it to be easy to ask their pharmacist questions about their medicines, however they may not recognise the value in doing so.

Figure 46: Patients' responses to the discharge medicines experience questionnaire (base 61).

Table 33: Patients' mean responses to the Medicines Experience Survey by site, gender deprivation and ethnic minority (base = 61)

Question	All (SD)	Site 1 male (SD)	Site 1 female (SD)	Site 2 male (SD)	Site 2 female (SD)	Low Deprivation (SD)	Medium deprivation (SD)	High deprivation (SD)	Ethnic minority (SD)
When I left the hospital, I clearly understood the purpose for taking each of my medicines	3.72 (1.44)	3.67(4.53)	3.67 (1.41)	3.55 (1.53)	4.33 (1.00)	3.27 (1.55)	3.94 (1.35)	3.75 (1.46)	4.00 (1.50)
I am confident I can take my medicines as instructed	4.51 (1. 13)	4.43 (1.21)	4.33 (1.32)	4.59 (1.81)	4.67(0.71)	4.36 (1. 29)	4.89 (0.32)	4.34 (1.33)	3.89 (1.69)
It is easy for me to ask my community pharmacist questions about my medicines	4.34 (1.06)	4.05 (1.32)	4.56 (0.72)	4.45 (1.01)	4.56 (0.73)	4.27 (1.27)	4.67 (0.69)	4.19 (1.15)	4.11 (1.05)
When I left the hospital, I clearly understood how to take each of my medicines	4.41 (1.17)	4.14 (1.42)	4.22 (1.30)	4.55 (1.06)	4.89 (0.33)	4.55 (1.04)	4.64 (0.97)	4.19 (1.38)	4.11 (1.54)
It is easy for me to understand the instructions I was given for my medicines	4.33 (1.21)	3.90 (1.55)	4.56 (1.01)	4.42 (1.05)	4.89 (0.33)	4.33 (1.21)	4.72 (0.75)	4.22 (1.34)	4.33 (1.32)
It is easy for me to ask my GP questions about my medicines	3.75 (1.41)	4.05 (1.16)	4.00 (1.58)	3.72 (1.49)	2.89 (1.45)	3.91 (1.70)	3.83 (1.30)	3.66 (1.41)	3.56 (1.42)
I currently understand the purpose for taking each of my medicines	4.21 (1.21)	3.90 (1.30)	3.89 (1.45)	4.32 (1.17)	5.00 (0.00)	4.18 (1.17)	4.56 (0.98)	4.03 (1.33)	4.22 (1.30)
The healthcare team work together to support me in managing my medicines	3.36 (1.53)	3.76 (1.41)	2.44 (1.59)	3.59 (1.65)	2.78 (0.97)	3.18 (1.47)	3.50 (1.72)	3.34 (1.47)	3.22 (1.56)
It is easy for me to get all the information I need about my medicines	4.15 (1.17)	4.24 (1.78)	4.00 (1.58)	4.27 (0.88)	3.78 (1.39)	3.90 (1.17)	4.44 (1.04)	4.06 (1.24)	3.56 (1.42)

Table 34: Inter-item correlations for the Medicines Experience Scale (MES)

	Understood the purpose on leaving hospital	Confident I can take my medicines	Easy to ask my pharmacist	Clearly understood how to take on	Easy to understand instructions	Easy to ask GP questions	Currently understand purpose	Healthcare team work together	Easy to get information
Understood the purpose on leaving hospital	1.00	0.20	0.20	0.49	0.23	0.12	0.56	0.13	0.23
Confident I can take my medicines	0.20	1.00	0.07	0.57	0.58	0.256	0.24	0.27	0.16
Easy to ask my pharmacist	0.20	0.07	1.00	0.29	0.17	0.08	0.15	-0.19	-0.02
Clearly understood how to take on leaving hospital	0.48	0.57	0.29	1.00	0.52	0.27	0.56	0.20	0.25
Easy to understand instructions	0.23	0.58	0.17	0.52	1.00	0.14	0.30	0.08	0.08
Easy to ask GP questions	0.12	0.26	0.08	0.27	0.14	1.00	0.01	0.41	0.35
Currently understand purpose	0.56	0.24	0.15	0.56	0.30	0.01	1.00	0.13	0.14
Healthcare team work together	0.13	0.27	-.019	0.20	0.08	0.41	0.13	1.00	0.49
Easy to get information	0.23	0.16	-0.02	0.25	0.08	0.35	0.14	0.49	1.00

Table 35: MES reliability item by item

Item	Scale Mean if Item Deleted	Cronbach's Alpha if Item Deleted
Understood the purpose on leaving hospital	33.07	0.71
Confident I can take my medicines	32.28	0.70
Easy to ask my pharmacist	32.44	0.75
Clearly understood how to take on leaving hospital	32.38	0.67
Easy to understand instructions	32.46	0.71
Easy to ask GP questions	33.03	0.73
Currently understand purpose	32.57	0.71
Healthcare team work together	33.43	0.73
Easy to get information	32.64	0.72

MES means for patients overall and by site, gender, gender, deprivation band and for ethnic minority patients are shown in Figure 47. Higher MES values were measured for both males (33.00, SD 5.62) and females (33.22, SD 4.09) at Site 2. At Site 1 lower MES values were observed for females (31.11, SD 7.59) and males (32.10, SD 7.25). Mean MES values were also explored for those from low, medium and high areas of deprivation. Values for those patients from low and high areas of deprivation did not differ greatly (low deprivation = 31.55, SD 5.99, high deprivation = 31.60, SD 6.81) whilst higher mean values were recorded for those from areas of medium deprivation (34.50, SD 5.04). Patients from ethnic minorities had less positive MES values than other patients (30.89, SD 6.29).

7.3.1 Constructs within the question scale

A principal components analysis (PCA) was undertaken to explore any underlying constructs within the scale and determine whether the data could be formed into valid subscales.

The PCA was undertaken on the original nine items with an orthogonal (varimax) rotation. There is some debate about the sample size necessary to perform a PCA: Field described how views on the ratio of participants to variable range from 5–15 (in this data there is a ratio of 6.7).[301] He goes on to describe empirical research that concludes that factors with four or more loads of 0.6 are reliable.

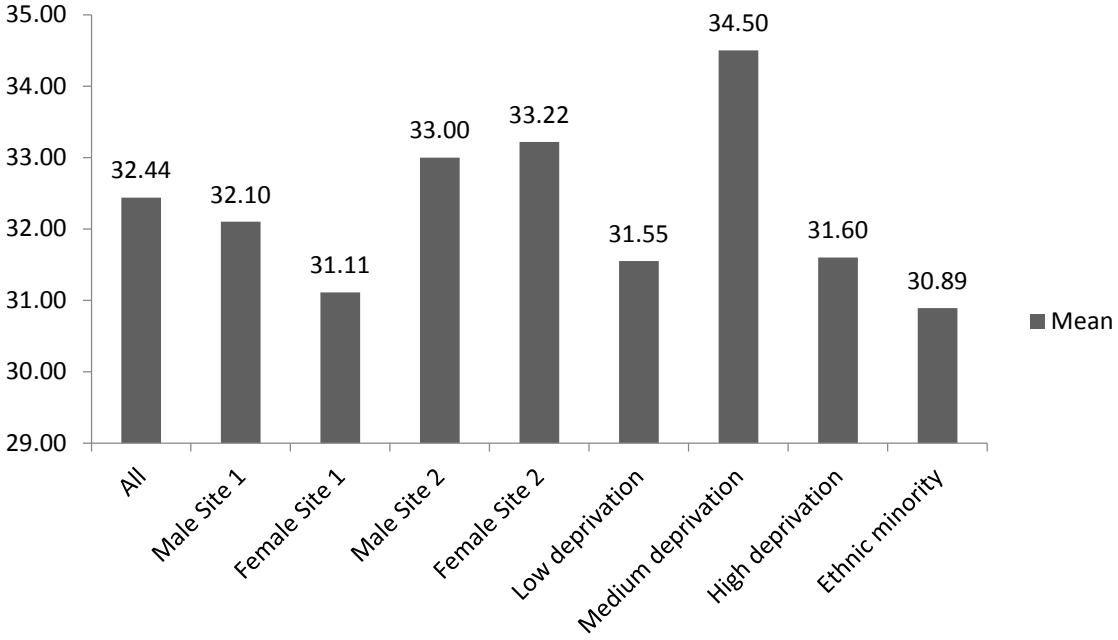

Figure 47: MES means by gender, site and deprivation

A Bartlett's test of sphericity indicated that overall the inter-item correlations were large enough to conduct the analysis (X^2 (36) = 148.45, p<0.001) and a Kasier-Meyer-Olkin measure of sampling adequacy (0.72) was good overall and either adequate or good for each individual variable (values ranged between 0.610 – 0.778 which are above the minimum accepted value of 0.5). The anti-image correlation matrix (which presents the amount of variance not explained whilst controlling for the effects of the other variables) is presented in Table 36 with the Kasier-Meyer-Olkin measures of sampling adequacy highlighted. Each of the off-diagonal negative correlations was also small, which indicates the presence of underlying factors.

The scree plot in Figure 48 demonstrates several points of inflection indicating several components; however as the sample size is small three factors with an eigenvalue (the substantive importance of each component) in excess of 1 were extracted. Those three components and their loading factors are presented in Table 37. In combination they explained 65.3% of the variance. The first component comprised of two items about patients' understanding of the purpose of their medicine and one question about the ease of asking community pharmacy questions about their medicines, yet this last item fails to load strongly onto any of the components and does not logically fit within this component. This component explained 34.5% of the variance.

The second component, explaining 18.2% of the variance, comprised of items about patients' confidence in their ability to take medicines and understanding of how to take medicines. The third component, explaining 12.6% of the variance, comprised of items about the ease of asking questions and getting information from patients' GPs and an item about the healthcare team working together to support them. The three components were named: (1) Medicines understanding; (2) Medicines self-efficacy; and (3) Medicines support.

An analysis of the components as subscales was performed. Subscale 1 (medicines understanding) had a reliability statistic of α = 0.58, and an improved reliability statistic of α = 0.71 if the item '*It is easy for me to ask my community pharmacist questions about my medicines'* were removed, which makes sense given that the item does not logically sit well with the two other items in this subscale. Subscale 2 (medicines self-efficacy) had a reliability statistic of 0.79.

Table 36: The anti-image correlation matrix for PCA. 1 indicates the measure of sample adequacy

	Understood the purpose	Confident I can take my	Easy to ask my pharmacist	Clearly understood	Easy to understand	Easy to ask GP	Understand the purpose	Healthcare team work	Easy to get information
Understood the purpose on leaving hospital	*0.778*[1]	0.039	-0.080	-0.181	0.018	-0.029	-0.396	0.018	-0.134
Confident I can take my medicines	0.039	*0.706*[1]	0.084	-0.372	-0.431	-0.059	0.110	-0.177	0.065
Easy to ask my pharmacist	-0.080	0.084	*0.6101*[1]	-0.217	-0.058	-0.113	0.031	0.250	-0.004
Clearly understood how to take	-0.181	-0.372	-0.217	*0.765*[1]	-0.180	-0.156	-0.377	0.011	-0.094
Easy to understand instructions	0.018	-0.431	-0.058	-0.180	*0.774*[1]	0.010	-0.084	0.083	0.008
Easy to ask GP	-0.029	-0.059	-0.113	-0.156	0.010	*0.718*[1]	0.186	-0.295	-0.147
Understand purpose	-0.396	0.110	0.031	-0.377	-0.084	0.186	*0.695*[1]	-0.097	0.037
Healthcare team work together	0.018	-0.177	0.250	0.011	0.083	-0.295	-0.097	*0.633*[1]	-0.391
Easy to get information	-0.134	0.065	-0.004	-0.094	0.008	-0.147	0.037	-0.391	*0.720*[1]

Table 37: PCA component loading values

Component 1: Medicines Understanding (34.54% of variance)	**Component 1 loading**	**Component 2 loading**	**Component 3 loading**
When I left the hospital, I clearly understood the purpose for taking each of my medicines	**0.84**	0.05	0.16
It is easy for me to ask my community pharmacist questions about my medicines	**0.40**	0.23	-0.29
I currently understand the purpose for taking each of my medicines	**0.82**	0.16	0.06
Component 2 : Medicines self-efficacy (18.19% of variance)			
I am confident I can take my medicines as instructed	0.08	**0.85**	0.22
When I left the hospital, I clearly understood how to take each of my medicines	0.60	**0.61**	.019
It is easy for me to understand the instructions I was given for my medicines	0.19	**0.83**	-0.01
Component 3: Medicines support (12.55% of variance)			
It is easy for me to ask my GP questions about my medicines	-0.03	0.28	**0.65**
The healthcare team work together to support me in managing my medicines	0.01	0.09	**0.85**
It is easy for me to get all the information I need about my medicines	0.23	-0.03	**0.77**

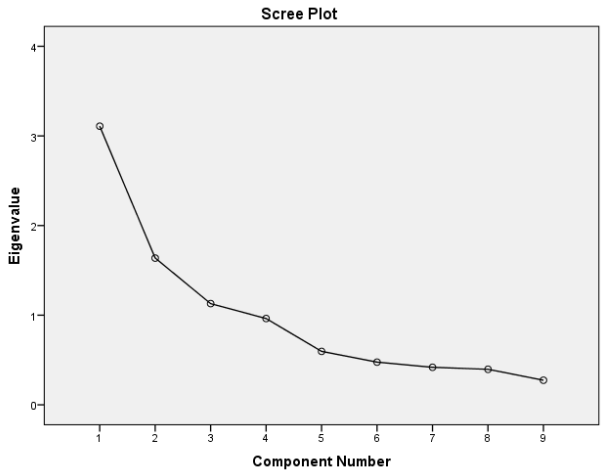

Figure 48: A Scree plot mapping the PCA components and their eigenvalues.

Subscale 3 (medicines support) had a reliability statistic of α = 0.68. As only one subscale had a reliability statistic in which was higher than that of the eight-item scale (0.75), and that scale only contained two items, it was judged appropriate to conduct analysis on the larger, eight-item scale.

Once the final components of the MES had been established it was decided that exploratory modelling using the MES as a dependent variable would offer some insight into the impact of patient demographics and their medicines management social networks on the scale values, taking into consideration the fact that the experience of a patient safety incident would impact on the MES value. The results of that analysis are described in the following sections.

7.4 Patient safety incidents after hospital discharge

During interviews patients were asked whether anything had happened since they left hospital to make them more or less confident in their medicines. Their responses were recorded and data were extracted and summarised in table format, which is presented in Appendix 6. Data were reviewed by two clinical researchers to determine whether patients' reports indicated that a patient safety incident had occurred using the NPSA definition of a patient safety incident, quoted below:

"A patient safety incident is any unintended or unexpected incident which could have or did lead to harm for one or more patients receiving NHS care."[14]

In total events relating to 31 patients were extracted and assessed. A Cohen's kappa (κ) agreement statistic was calculated based on the ratings of two

assessors on three values: yes; no; and unsure. The results of the ratings are shown in Table 38. Assessors agreed that 16 of the 31 extracted events (51.6%) were patient safety incidents.

Table 38: Summary of safety incident assessments by two clinical researchers

	Assessor 2		
Assessor 1	No	Yes	Unsure
No	11	1	1
Yes	1	16	0
Unsure	1	0	0
Total	13	17	1

7.5 Standardising the MES values

In advance of statistical modelling, MES values were standardised by calculating their logarithm base 10 values. Standardisation is important to obtain minimum skew in the data so a linear relationship may be measured and to minimise the impact of outliers on any statistical models fitted to the data.

A logarithm base 10 standardisation is suitable for right skewed data with positive values. Figure 49 is a histogram of the standardised MES values whilst Figure 50 is a boxplot of the values with outliers highlighted. Standardised values on the scale ranged from 1.18–1.60 with a mean of 1.50 (SD 0.10). Figure 51 is a normal Q-Q plot of the observed versus expected values of the standardised scores and Figure 52 is a normal Q-Q plot of scale observed versus expected normal values.

Exploratory MES analysis

Two-tailed independent samples t-tests indicated a non-significant associations between standardised values of the Medicines Experience Scale and gender ($t(59) = 0.144$, $p = 0.886$) and site ($t(59) = -0.959$, $p = 0.342$). A range of other categorical variables were also tested and the results of those t-tests are shown in Table 39. One test yielded a significant result: unsurprisingly those patients who had reported a safety incident (n = 16) reported less positive experiences with their medicines (m = 1.46, SE = 0.01) than those who did not

(n= 44; m = 1.52, SE 0.02) (t (58) = 2.189, p<0.05, r = 0.28). A subsequent series of correlations were explored between interval variables and values on the standardised MES. They are presented in Table 40. Only one variable was significantly correlated: the number of weak components in patients' networks was significantly negatively correlated with values on the standardised MES (r = 0.285, p<0.05), indicating a linear relationship between higher numbers of weak network components and less positive experiences. Lower degree scores values also negatively correlated, indicating that patients with more network members have less positive experiences, although this failed to reach statistical significance.

7.6 Modelling patients' post-discharge medicines experience

Using the results of the exploratory data analysis, a multiple linear regression model using the standardised MES as a dependent variable was constructed. A hierarchical blockwise approach was used to ascertain the change in squared residual values as each variable was added to assess how effective each model was in explaining MES variation and the impact of additional variables of the significance of the model. The binary variable recording whether patients had reported a safety incident was included as a control variable. Some variables were excluded to avoid multicollinearity, which occurs when there are strong positive or negative correlations between independent variables. For example, the number of weak components was significantly correlated with network density and network degree.

In total eight multiple linear regression models were fitted and each was statistically significant in explaining a proportion of the variation in the standardised MES. Each of these statistical models is presented in Table 41 with overall F statistic for the analysis of variance, the value of the squared residuals and the parameter estimates. The final model was selected as it explains the most variation in the MES (29%), whilst controlling for the most demographic variables. The addition of further predictors produced a non-significant model.

Table 39: Two-tailed independent sample t-tests on the standardised MES – significant tests highlighted *

Variable	*t* (df =59)	*p*
Gender	0.144	0.886
Site	-0.959	0.342
Ethnic minority	1.217	0.228
Deprivation (low vs medium)	-1.365	0.184
Deprivation (low vs high)	0.106	0.916
Deprivation (medium versus high)	1.529	0.133
Spouse present in the network (equal variances not assumed)	-1.348	0.184
Highly valued spouse	-0.994	0.324
GP present in the network	0.901	0.371
Highly valued GP	-1.228	0.224
Community pharmacist present in the network	-0.117	0.908
Highly valued CP	0.716	0.447
Cardiac rehab / HF nurse present in the network	0.533	0.596
Highly valued CR / HF	0.595	0.554
Safety incident	2.189 (df=58)	0.039 *

Table 40: Correlations with the standardised MES – significant correlations highlighted *

Variable	Pearson correlation (r)	*p*
Age	0.134	0.302
Number of weak components	-0.285	0.028 *
Proportion of weak components	0.007	0.960
Density	- 0.015	0.908
Degree	-0.201	0.121
Lay degree	-0.096	0.461
Prof degree	-0.125	0.339
Diversity	-0.033	0.803
Broker	-0.114	0.387
Normalised Broker	0.123	0.348
Ego between	-0.128	0.331
Normalised ego betweenness	0.029	0.947

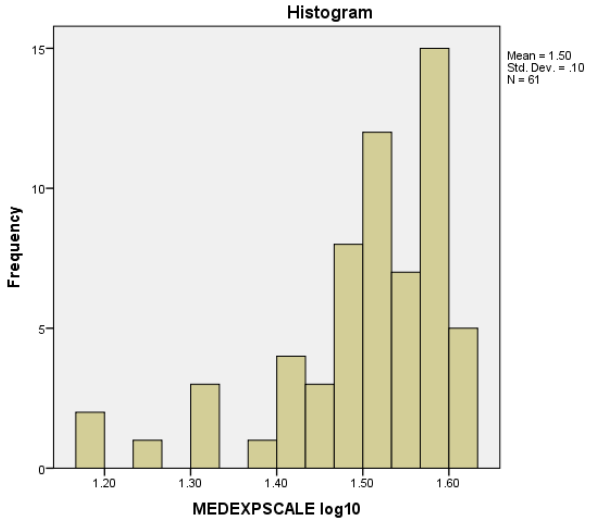

Figure 49: A histogram of the log10 MES values

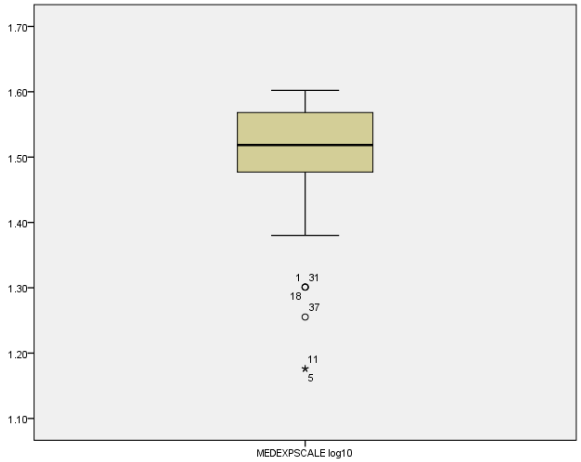

Figure 50: A boxplot of the log10 MES values

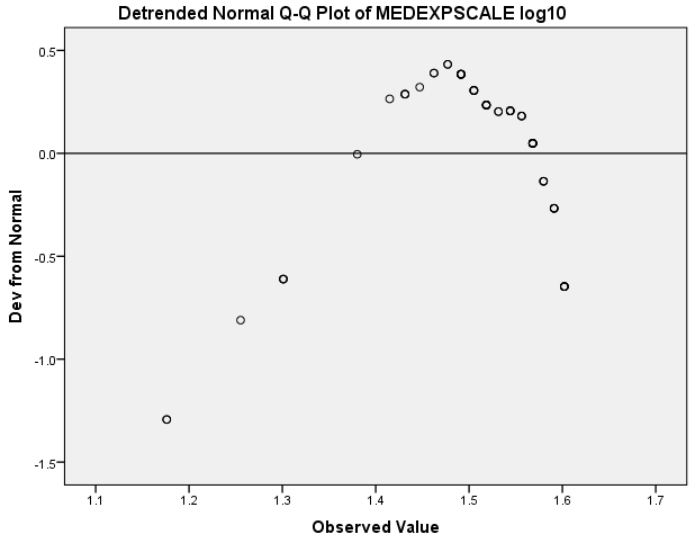

Figure 51: A Normal QQ plot of observed log10 MES values

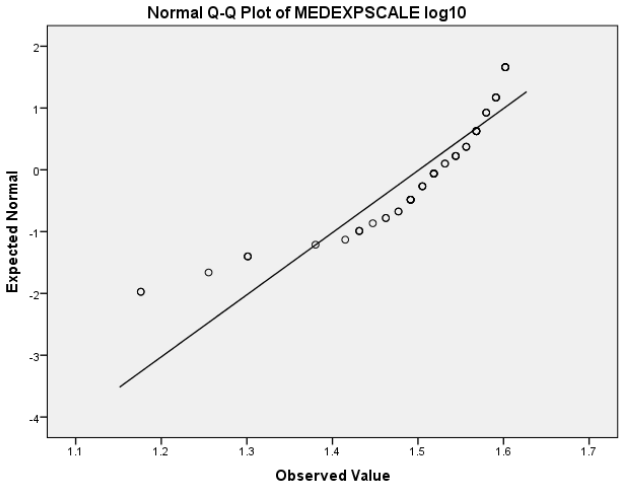

Figure 52: A normal Q-Q plot of the observed vs expected log10 MES values

The regression model equation therefore is:

y (MES) = 1.497 – 0.073 (safety incident) – 0.020 (weak network components) + 0.019 (spouse in network) – 0.065 (ethnic minority) + 0.038 (deprivation medium) + 0.05 (deprivation high) + 0.017 female + 0.001 (age) + 0.30 (Site2).

The model overall is statistically significant ($p<0.0005$), and two predictor variables within it have statistically significant parameter estimates. Patients who were assessed to have experienced a patient safety incident had significantly lower MES values than other patients (-0.073 (CI -0.128, -0.017)) ($p<0.05$), whilst controlling for gender, age, site, ethnicity and deprivation. Those with greater numbers of weak components in their networks also had significantly lower values on the scale (-0.020 (CI -0.035,-0.004)) ($p<0.05$), again controlling for the same demographic variables.

Two cases had standardised residuals greater than two and none had greater than three, and as this figure is less than 5% of the sample size it can be concluded that there are no outliers with a significant influence on the regression model. Cook's distance measures the overall influence of a case on the regression model. For the selected model, no values of Cook's distance were greater than 1 (range 0.00-0.311), which indicates that no individual case has an overly large influence. A case-by-case analysis of standardised DFBeta values – which calculate the differences in parameter estimates should cases be removed – were not greater than +/- 1; and only one case had a Mahalanobis' distance value greater than 15 (15.033) (which was case 2-3). This statistic indicates whether cases are outliers. The average leverage for the model is 0.167 and no cases had a leverage value greater than twice the average leverage, again indicating that no case is overly influential in fitting the model. Together the results of these tests suggest a high degree of confidence that no one case exerted too great an influence of the model parameter predictions.

Model assumptions were tested by examining the residuals for heteroscedasticity and non-linearity. Figure 53 is a scatterplot of the standardised predicted values of the regression model versus the standardised residuals showing a relatively random array of values with no curves, which indicates limited heteroscedasticity and non-linearity Figure 54 is the normal

probability plot of the regression model residuals, showing relatively normally distributed residuals, and Figure 55 is a histogram of the residuals with a normal curve indicating their normal distribution. It was judged that these assumptions had not been violated.

Table 41: Multiple linear regression models explaining MES variation

Model	F (df)	*p*	R^2	Change (p)	Constant (SE) (95% CI)	Constant (p)	Coefficients (SE)	95% CI	Coefficients (p)
1	4.437 (59)	0.039 *	0.07		1.519 (0.015) (1.490–1.548)	<0.0005 ***	Safety incident -0.059 (-0.028)	-0.116 – -0.003	0.039 *
2	4.469 (59)	0.016 *	0.135	0.044*	1.586 (0.036) (1.515–1.658)	<0.0005 ***	Safety incident -0.052 (0.028) Weak components -0.015 (0.007)	-0.108– -0.003 -0.030–0.000	0.063 0.044 *
3	3.762 (59)	0.016 *	0.168	0.147	1.567 (0.038) (1.491–1.642)	<0.0005 ***	Safety incident -0.059 (-0.028) Weak components -0.015 (0.007) Spouse present in the network 0.036 (0.024)	-0.114– -0.003 -0.030–0.000 -0.013–0.084	0.038 * 0.053 0.147
4	4.437 (59)	0.005**	0.232	0.037	1.559 (0.040) (1.520–1.679)	<0.0005 ***	Safety incident -0.071 (-0.027) Weak components -0.017 (0.007) Spouse present in the network 0.024 (0.024) Ethnic minority -0.075 (0.035)	-0.126– -0.016 -0.032– -0.003 -0.024–0.073 -0.145-0.005	0.012 * 0.021 * 0.124 0.037 *
5	2.997 (59)	0.014 *	0.252	0.472	1.592 (0.49) (1.493–1.690)	<0.0005 ***	Safety incident -0.069 (-0.028) Weak components -0.018 (0.007) Spouse present in the network 0.019 (0.025) Ethnic minority -0.070 (0.036) Deprivation medium vs low 0.034 (0.036) Deprivation high vs low 0.002 (0.035)	-0.125– -0.014 -0.033– -0.003 -0.032–0.070 -0.142–0.003 -0.038–0.108 -0.068–0.071	0.015 * 0.019 * 0.461 0.059 0.351 0.965
6		0.023 *	0.258	0.585	1.587 (0.050) (1.487 – 1.688)	<0.0005 ***	Safety incident -0.069 (-0.028) Weak components -0.019 (0.008) Spouse present in the network 0.022 (0.026)	-0.125– -0.013 -0.034– -0.003 -0.031–0.074	0.015 * 0.019 * 0.461

							Ethnic minority -0.073 (0.037)	-0.147–0.001	0.059
							Deprivation medium vs low 0.036 (0.036)	-0.037–0.108	0.351
							Deprivation high vs low 0.005 (0.036)	-0.066–0.076	0.965
							Gender 0.015 (0.036)	-0.040–0.070	0.585
7		0.030 *	0.270	0.351	1.518 (0.089) (1.339 – 1.697)	<0.0005 ***	Safety incident -0.071 (-0.028)	-0.127– -0.015	0.014 *
							Weak components -0.018 (0.008)	-0.033– -0.003	0.021 *
							Spouse present in the network 0.022 (0.026)	-0.031–0.074	0.408
							Ethnic minority -0.067 (0.037)	-0.142–0.008	0.077
							Deprivation medium vs low 0.034 (0.036)	-0.038–0.107	0.345
							Deprivation high vs low 0.004 (0.036)	-0.067–0.075	0.911
							Gender 0.016 (0.027)	-0.039–0.071	0.554
							Age 0.001 (0.001)	-0.001–0.003	0.351
8		0.031	0.291	0.233	1.497 (0.090) (1.315 – 1.678)	<0.0005 ***	Safety incident -0.073 (-0.028)	-0.129– -0.017	0.011 *
							Weak components -0.020 (0.008)	-0.035– -0.004	0.013 *
							Spouse present in the network 0.019 (0.026)	-0.033–0.072	0.461
							Ethnic minority -0.065 (0.037)	-0.140–0.010	0.087
							Deprivation medium vs low 0.038 (0.036)	-0.035–0.110	0.345
							Deprivation high vs low 0.05 (0.035)	-0.066–0.076	0.911
							Gender 0.017 (0.027)	-0.038–0.072	0.554
							Age 0.001 (0.001)	-0.002–0.003	0.351
							Site 2 0.30 (0.25)	-0.020–0.079	0.233

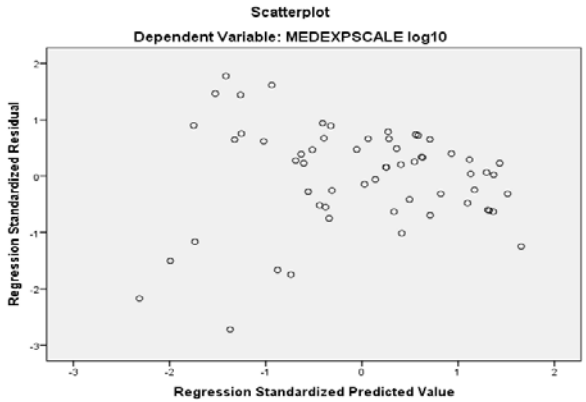

Figure 53: A scatterplot of the standardised predicted values of the regression model versus the standardised residuals.

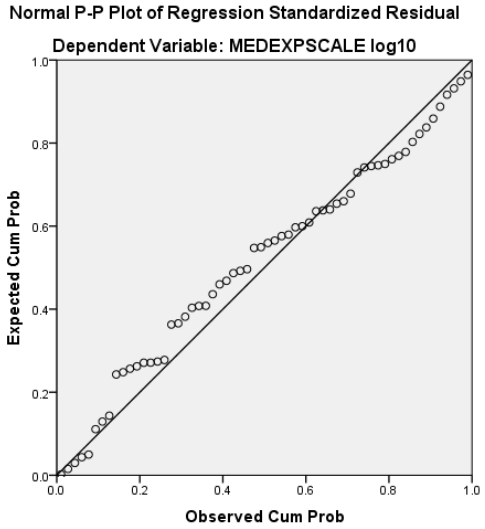

Figure 54: A normal probability plot of the regression model residuals.

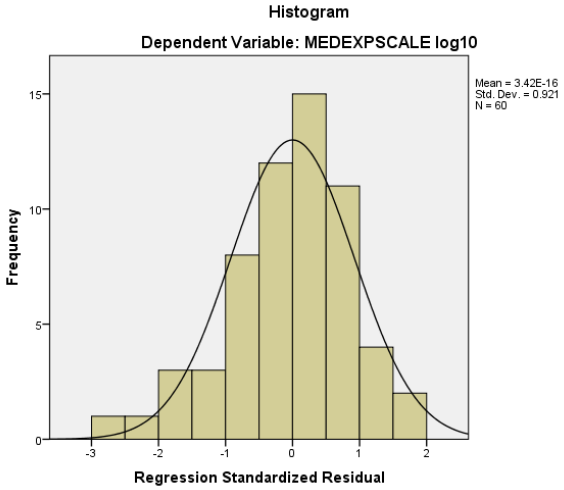

Figure 55: A histogram of the regression model residuals.

7.7 Discussion

In this chapter a reliable medicines experience scale was created and explored from a series of questions put to patients six weeks after their hospital discharge. The question set explored patients' understanding of their medicines, their access to HCPs, their confidence to take their medicines, and their perceptions of the multi-disciplinary nature of their care. In answering these questions patients reported on the whole positive experiences with their medicines, which were not reflected in their qualitative accounts. Patients were less positive about their views of the healthcare team working together to support them in managing their medicines. There were no convincing subscales in the data, but this may be a reflection of the relatively small number of questions in the scale. Exploratory data modelling indicated that the number of weak components in patients' networks – which are the number of individuals or groups of individuals in the ego-network connected only to the patient – impacted on their experiences with their medicines, whilst controlling for socio-demographic factors and whether the patient had disclosed a patient safety incident during their interview. This indicated that a lack of connectivity in patients' ego-networks negatively impacted on their experiences with their medicines.

7.8.1 Creating the scale

It was necessary to create a new question set to attempt to capture patients' experiences specifically with their discharge medicines as no suitable measure existed. A review of measures showed that instruments recorded: medicines use self–efficacy; [290] adherence;[182,183,350] beliefs about medicines;[351] satisfaction with information about medicines;[236] general transitions and continuity;[58] and medicines discrepancies.[291] Yet no measure was identified that recorded patients' experiences of leaving hospital, although there is evidence that the patient experience can be linked to patient safety and clinical effectiveness for many different health conditions.[352] Doyle et al. argue, based on their literature review, that a focus on improving the patient experience will also impact on the safety and effectiveness of the care patients receive;[352] however no studies were identified that linked patients' experiences with their medicines to patient safety. This measure has gone some way to developing such a tool, however more work needs to be done to refine and validate it.

It was noticeable that in interviews patients recounted experiences that were less positive than their responses to the questionnaire and they had less positive assessments of their own understanding of their medicines than they were willing to admit when they were asked to definitively assess their abilities by selecting an answer option on a questionnaire. Including no reverse response options may also have constituted a weakness. Reversing questionnaire items (for example through negatively wording some questions) is a widely used approach to preventing acquiescent or inattention response bias in surveys, although there is now some debate over the reliability of such methods.[353]

The question set together formed a reliable scale, although the Cronbach's alpha statistic was towards the lower end of what is generally thought to be acceptable.[301] Removing the community pharmacy question improved the alpha statistic slightly, and as this question had low correlations with other questions, it is possible that it measured something that it did not set out to measure. For instance, the question *'It is easy for me to ask my community pharmacist questions about my medicines'* intended to measure self-efficacy to access the clinical services of a community pharmacist. It may, however, actually have measured whether patients found their community pharmacist accessible, rather than whether they would find it appropriate to or have the confidence to ask their pharmacist questions about their discharge medicines, or indeed whether they would wish to. Qualitatively in Chapter 5, patients reported preferring to ask their GP if they had questions about their medicines or perceiving the GP or hospital doctor to be the superior source of information or decision-making, which is also a finding in other studies.[116,354–356]

7.8.2 Exploratory modelling of the data

Exploratory modelling of the Medicines Experience Scale attempted to unite the datasets collected from patients: aspects of their ego-networks structure, their experiences of patient safety incidents, along with demographic data were used as independent variables in a multiple linear regression. When controlling for other variables, including whether a patient experienced a safety incident, the perceived number of weak components in their network was found to have a significant impact on the scale value. The analysis indicates that for this group of cardiology patients, the lack of connectivity in their networks has an impact

on their medicines experiences. However, the findings should be treated with some caution: it is possible that this result is influenced by responses to one item in the MES exploring patient views of the healthcare team working together to support them in managing their medicines. However, the scale alpha statistic indicated that it was a robust measure, i.e. the questions adequately measured a single construct. A larger sample and further refinement of the scale is now needed to explore these potential weaknesses and generate further evidence to confirm or refute the findings of this study.

7.8.3 Further development of the Medicines Experience Scale

Whilst the questionnaire used in this research formed a reliable scale, several problems were noted during the qualitative semi-structured interviews with patients. For example, in one or two instances patients explained that they did not understand their medicines, yet when completing the questionnaire they still responded positively to the items exploring their understanding, possibly displaying a social desirability bias that did not come into play during interviews.[357] This finding also indicates how qualitative work can often draw out perceptions and experiences from patients more effectively than quantitative instruments and use that data to develop survey instruments.[358] The questionnaire would benefit from revision; the qualitative interview data described in Chapter 6 indicate how important the practical and emotional support of friends and family are in enhancing patients' abilities to self-manage their medicines. Therefore, a question about having or needing help with medicines may enhance the survey as tool to measure experience. The questionnaire may also usefully explore the interventions that patients are required to make to ensure they get the correct medicines when they need them after they have left the hospital to further explore the patient role in system resilience.[67,359] This could be done through asking a question about their experiences providing medicines information to HCPs, as described in Chapter 6.

Chapter 8 – General discussion

8.1 Introduction

This thesis has explored cardiology patients' experiences of and roles in medicines management from the point of discharge in two hospitals, until approximately six weeks after they arrived home. In the first instance, an observational study described what patients were told about their medicines when they left hospital and identified the contributory and protective factors that might impact on medicines safety at discharge. Secondly, a social network analysis of the medicines management system as perceived by patients identified the range of HCPs and personal contacts who operate within that system.

The research described has employed a range of methods: structured and unstructured observation; semi-structured interviews; social network analysis; and survey. Analysis methods included descriptive statistics, the application of the YCFF, social network structural analysis, thematic analysis, principal components analysis, and linear regression. One of the strengths of this research is how data triangulated to generate a clear picture of patients' experiences of medicines management when their care was transferred after a period in hospital. Complementary qualitative and quantitative methods were able to measure and describe aspects of patients' discharge medicines management ego-networks. Triangulation of data collected through mixed methods made it possible to verify the results of different stages of the research.[221] Evidence collected at different stages of the study converged: for example, the results of observations made on wards and the identification of individual and patient factors as contributory factors to potential medicines-related safety incidents were validated by patients' retrospective accounts of their experiences of being discharged from hospital. Further triangulation was achieved through different means. Firstly, collecting both observation and interview data over an eight month period meant that data collected at different times contributed to the same results; secondly, data were collected in two distinct healthcare economies, which meant that data from different places triangulated; and finally data were collected from different groups – staff and patients – which provided complementary findings.

The aim of this chapter is to discuss the studies' findings and their implications for patients, and for policy and practice. Firstly, it will summarise the key findings from each chapter, then it will discuss those findings, relating them to other research and policy.

8.2 Summary of chapter findings

Chapter 4 described the results of an observational study of hospital discharges. It identified a lack of consistency in the way patients were informed about their medicines during and after their hospital discharge. At discharge, nurses most commonly told patients about the timing of their medicines but rarely told them about how to take them or the side effects they might experience. Nurses in the discharge lounge told patients less about their medicines than nurses on the ward and the discharge discussion was of a shorter duration in the discharge lounge. There was also variation in patients being told about whether and how the hospital would communicate with the patients' primary care team, and how patients should get repeat medicines. Most patients were not told this and staff also usually did not highlight the written discharge summary or other written medicines information to patients. Furthermore, the findings showed how hospital policy impacts on the quality and safety of the care that patients experience. Using the YCFF,[30] this study also suggested there was a range of factors that could contribute to an unsafe medicines management process at discharge as well as various defences against medicines safety incidents. Active failures included errors of execution, for example lapses, skill-based mistakes, and violations. Individual factors included the staff approach to discharging patients with medicines; and patient factors were also evident. Local working conditions gave rise to delays and interruptions; and problematic task characteristics, such as the complex nature of discharging patients with medicines, and internal patient transfer were also identified as contributory factors. Defences included individual staff and patient factors, such as note taking, and staff training and education where staff had specialist cardiology knowledge and experience.

Chapter 5 was an analysis of the structure of patients' medicines management ego-networks. Using SNA, it described how patients had developed networks of different sizes and compositions and how some had personal network members who they perceived to be current or former healthcare professionals. One in

four patients had no contact with their GP in the period after their discharge from hospital and almost half had no direct contact with a community pharmacist. The structure of medicines management was complex and individual to each patient; some patients managed the involvement of many healthcare professionals and healthcare support staff providing medicines-related care or services in the post-discharge period. Patients perceived low levels of connectivity between alters in their networks. The most connected professional network members were perceived to be cardiac rehabilitation and heart failure nurses, followed by GPs. Community pharmacists were perceived to be less connected than GPs, specialist nurses and hospital doctors, demonstrated by their comparative isolation in those networks where they did feature.

Chapter 6 presented a thematic analysis of semi-structured interviews with patients using a social network analysis framework to identify the content and function of patients' medicines management ego-networks. Content comprised information and advice about medicines from both professional and personal network members. Many patients described leaving hospital with insufficient information about their medicines, however, their networks were proactive and reactive in filling some of those gaps. Additionally, patients' cognitive and emotional attitudes about their medicines were influenced by their personal and professional contacts. Patients' medicines management networks were multi-functional: they provided medicines orientation, practical and emotional support as well as health condition management. Networks also risked patient safety though the failure of medicines management systems which meant that some patients did not fully understand changes made to their medicines and some patients were not able to access repeat medicines when they needed to.

Chapter 7 presented the results of the Medicines Experience Survey. It found that patients were on the whole positive about their medicines experiences, even though the experiences described during interviews were not positive. Patients were less positive in their evaluation of the extent of the healthcare team working together to support them in managing their medicines. The questions formed a reliable scale which was improved after removing one item, which was about the ease of being able to ask questions of a community pharmacist. A principal components analysis did not identify any convincing

subscales in the data. A multiple linear regression was used to perform exploratory analysis of the scale data. A model was fitted using the standardised MES as the dependent variable which explained nearly a third of the MES variation. Whilst the model overall was significant, only two individual independent variables were significant, they were the number of weak components patients' ego-networks (the number of unconnected people or groups of people) and whether patients had experienced a safety incident related to their medicines since their hospital discharge.

The following sections will discuss these findings in synthesis with reference to theory, current policy, practice and models in healthcare. I will begin with management of medicines at hospital discharge, the patient-centredness of medicines management and with systems, patient safety and patient resilience.

8.3 Medicines management at hospital discharge

Keeping patients safe from preventable harm from their medicines continues to be a worldwide and UK priority. Since this research was started, UK policy has recognised the risks faced by patients when they leave hospital (or transition) and issued guidelines to help make their care safer.[72,90,327]

Transitional care is a set of actions that co-ordinate continuity of care;[54] and patients in this study shared many of the experiences of those who participated in other research exploring medicines management experiences after discharge from hospital. For example, many experienced unsafe care, which has been previously measured in the form of ADEs,[47,48,50,51,166] although unsafe care may not have been the direct cause of an ADE. Others felt that they lacked information and understanding concerning their medicines;[137,143–145,147,148,164] and some perceived a lack of co-ordination of care.[144,150,166,167]

Transitional care is the responsibility of the person or organisation transferring care and the person or organisation receiving care. All the patients in this study experienced a care transfer, even though the extent to which they recognised their hospital discharge as a 'care transition' is debatable. It is likely that many patients viewed their return home as the end of an episode of care or the recovery from the health crisis that found them admitted into acute care. During

this period, patients themselves spanned the divide between hospital and primary care. They had a view of the care they received from different staff in different organisations that is not afforded to those staff. It is patients' *"unique observational position"*[305(p4)] which has been described in this research and which has laid bare some of the gaps in medicines management during their care transfer as well as illustrating where medicines management can work well.

By employing a systems-based analysis, the data yielded new insight into the extent of risk in the current system of discharge medicines management in two hospitals, along with the defences therein. Systems approaches have long been recommended as a way of reducing risk to patients.[13,360] Specifically, use of systems-based models has afforded a view about how poorly designed systems can negatively impact on the safety of medicines use.[63,79,98] However, the care components that potentially delivered safer care, synthesised from all the data presented in chapters 4–7, are detailed below:

1 Ward discharge rather than pre-transfer before discharge, in this case to a discharge lounge.
2 Accurate and timely reconciliation of patients' medicines in primary care.
3 Adequacy of individual preparation to use medicines after discharge.
4 Adequacy of explanation of changes made to medicines after discharge.
5 Consistency of follow-up in primary care to support medicines use.

In the UK in general, guidelines about what patients should be told about their medicines at discharge are vague, especially about how to prepare patients to self-manage their medicines.[72,91,92] In contrast, more in-depth information is offered in Australia by the Australian Pharmaceutical Advisory Council's *Guiding Principles to Achieve Continuity in Medicines Management*.[361] It specifies that patients need to be given sufficient information in a usable and understandable format to *"enable safe and effective use"*,[361(p39)] listing the information patients should receive in verbal and written formats:

- Stopped and started medicines;
- Active ingredients and brand names;
- Medicines purpose and actions;

- Medicines dose, route and administration schedule;
- Special directions and precautions;
- Side effects, interactions and how to manage them;
- How to store medicines;
- Safe disposal of medicines;
- Contact details for HCPs for follow-up information.

The way discharge is currently managed in UK hospitals may mean that providing this depth of information verbally is beyond hospital resource. In addition, evidence from ward observations and patient interviews in this research indicates that hospital may not be the best place to give detailed, verbal medicines information – the patients are still unwell and they are anxious to get home.

Both hospital sites had policies about discharging patients with medicines; however, neither gave adequate detail about how patients should be counselled about their medicines. This reflects current national guidelines that focus more on what healthcare organisations tell each other about patients' discharge medicines than what they should tell the patient.

Once home, many patients themselves co-ordinated the system that supplies their medicines, which is discussed in more detail in section 8.5.1, yet it was also clear that some patients were managing a system that lacked co-ordination and personalisation. Overall, observation, interview, ego-networks, and survey data together demonstrated how patients are at the centre of a complex and sometimes incomplete medicines management system involving multiple healthcare professionals and multiple medicines for various co-morbidities, which they must navigate and co-ordinate often without tailored support from HCPs. The system experienced by some patients in this research had insufficient barriers to prevent hazards becoming losses:[32,63] as many as a sixth of patients experienced patient safety incidents.

Whilst many patients in this study had contact with community pharmacy staff to obtain repeat medicines, interview data suggested that most of the patients did not access NMS or MUR services, even though they were all in the target group for MUR and they reported that it was easy to ask community pharmacists questions about their medicines. Social network data demonstrated how many

patients had no direct contact with a community pharmacist. Even the few patients who had an MUR did not fully benefit from it, either because they had not been given time to prepare or they did not understand the purpose of the consultation. Some patients also indicated that they perceived other HCPs, such as cardiac rehabilitation nurses and GPs, to have the necessary authority and expertise to discuss their medicines. Other patients did not themselves attend their community pharmacy to obtain their repeat medicines, sometimes because they felt too ill and a relative collected their medicines, or because they used community pharmacy delivery services. Community pharmacy could play a positive role in supporting discharged patients and recent work has found benefits to the formal integration of community pharmacy into the post-discharge pathway;[117] and community pharmacists themselves are positive about medicines review services.[347] There needs to be further work exploring how patients can benefit more fully from these services, which may involve a more formal referral from the hospital or from the GP, or home-based consultations, taking into account local cardiac specialist nurse contacts. There is some evidence that changing services or products so that they are the default option is a successful approach to behaviour change because it guards against inertia and the target audience perceives the default option to be the advised option.[362,363] The behavioural insights framework EAST – easy, attractive, social and timely – suggests services should be designed in a way that reduces the very barriers that prevent people from using them.[364] The framework sets out how services should be designed so they are:

- Easy to access and the default option. They should also be simple to understand;
- Attractive, so that they are incentivised or personalised;
- Social, so that people understand that others also access the service, and so that they also encourage their peers to do so;
- Timely, so that people are offered the service when they need it most and are receptive to it, and that the immediate perceived cost (or 'hassle') to people in using the service does not outweigh the perceived long-term benefit.

Redesigning the MUR using this framework may be a successful approach to increase the number of discharged patients who access the service. It would

become a default, personalised appointment made for patients with a community pharmacist at an easy-to-access location, which happens soon after they have left hospital. It needs clear, simple messages about its purpose and the immediate and long-term benefits, and an unequivocal message that all patients using certain groups of medicines will be asked to attend MURs.

8.4 Patient-centred medicines management

An important measure of the quality of healthcare is whether it provides care designed to meet individual patient's needs.[365] The literature review in Chapter 2 identified how patients' experiences did not reflect the person-centred care specified by current healthcare policy.[72,87,106] This research has demonstrated that every person's experience of medicines management is, in a sense, individual: each sociogram in Chapter 5 and Appendix 3 showed the different structures of care perceived by patients. However, the extent to which the care that patients experience is individualised or tailored to their needs and values is questionable. Yet there is a current drive to position patients as fully integrated into the healthcare systems and in receipt of patient-centred, individualised care. For instance, the Health Foundation offers a framework for person-centred care with four key principles:

- Care is co-ordinated;
- Care is personalised;
- Care supports people to recognise their own strengths;
- Care affords people dignity and respect.[366]

The NHS vision for individual participation is:

"*Patients and carers are involved in managing their own health, care and treatment. This means being involved in decisions about their care and having choice and control over the NHS services they receive."*[367]*(p13)*

Based on the qualitative interview data in Chapter 6, many of the patients who took part in this research would probably not recognise the care they experienced in these descriptions. Some could not easily access their GP and felt confused and isolated from support. NICE guidelines on medicines optimisation reinforces that the care patients receive should be patient-centred, although health professionals should understand the extent to which patients wish to be involved in decisions about their treatment.[72] The parental model of

healthcare (one where the clinician would interpret the optimal treatment for a patient based on its clinical relevance) was probably highly familiar (and acceptable) to many of the patients in this study. Indeed, some patients talked about the trust that they had in the prescribers of their medicines to give them safe and effective care, which negated their need to understand more about their treatment. Many were indeed grateful for the good care they perceived. However, some patients in this study described situations where access to services and management of their treatment was out of their control, their ego-networks highlighted the perceived lack of communication between their healthcare providers, and many described how the care they received regarding their medicines fell short of their expectations. To begin with, both observation and interview data indicated that their experiences of being discharged from hospital were highly varied. They were not involved in decisions about the timing and location of their discharge and it was not apparent that their individual needs or preferences were taken into account when deciding the level of medicines information to give them. The experiences of these patients reflect findings elsewhere: readmitted patients have described how their capabilities and resources and knowledge of their condition and medicines history was ignored by HCPs during discharge.[368] The patient-centredness of discharge in nine hospitals in five countries has been specifically examined with little evidence of a patient-centred approach.[369] The study found that there was a lack of care provider prioritisation of discharge consultations and that discharge information was given too quickly, used jargon, and was unclear, with little time for patients' questions. It also described how patients' abilities to self-manage their care after discharge were often not critically assessed by hospital staff.

In this research, it was clear that many factors combined to inhibit patient-centred encounters, many of which align with the conceptual framework proposed by Mead and Bower for doctors (see Figure 56).[370] These were:

- Consultation-level influences: work pressures faced by staff, interruptions whilst discharging patients, the presence of third parties (other than those the patient wished to be there) and time limitations.
- Clinician factors: the nurse's knowledge of the patient; attitudes towards the importance of discharge discussions; and knowledge of the condition and medicines.

- Patient factors: attitudes and expectations.

Mead and Bower's model maps other dimensions influencing patient-centredness, such as remote 'shapers', which include cultural norms and formal and informal learning, professional context; and additional clinician and patient factors such as age and personality. These were not looked for in this research, however it may be the case that alternative research methods, such as qualitative interviews with staff members, would uncover these additional influencers in the hospital discharge context.

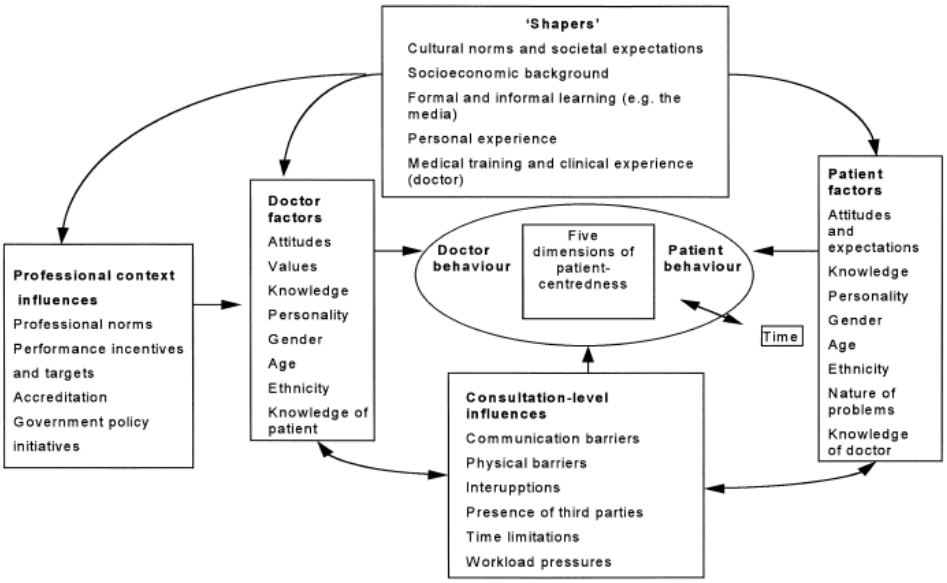

Figure 56: A model of a patient-centred relationship, from Mead and Bower.[370] Reproduced with kind permission.

An important limitation of the Mead and Bowers model it that it deals only with single clinician-patient relationships, which is also reflected in other studies of patient-centredness which focus on preferences, therapeutic alliances, and the balance of power within single patient-practitioner relationships.[371–374] Observations, interviews and ego-networks highlighted the multi-professional, multi-organisational context in which patients experience healthcare across transitions – and even in single settings – with different clinicians in different roles performing specialist functions at different times and different locations.

Instead of a one-to-one patient-clinician relationship, patients in this research mostly experienced one-to-many relationships. Even if patients experienced individual, patient-centred encounters with a clinician, such as a cardiac rehabilitation nurse, the overall system itself may not have been calibrated to

deliver patient-centred medicines management at all its touch points. This is reflected in patients' ambivalent responses to the item on the medicines experience survey (see Chapter 7) that probed their opinion of whether the healthcare team works together to support them in managing their medicines, and the significant impact that disconnectedness in patients' networks had on their MES value. The ego-networks developed for each patient were mostly very loosely connected, which also demonstrated patients' views of the lack of co-ordination between their care providers.

Questions must be raised, therefore, about how an integrated patient-centred medicines management process could be designed and embedded into policy to make it an actionable goal for all care providers within healthcare economies. Interventions have attempted to enhance the person-centredness of medicines management, although few have been delivered by multidisciplinary teams.[375] Previous work has to some extent explored this issue and proposed allocating specific care providers in primary care who would help patients through the transfer, acting as a bridge, being an advocate and communication and information manager, helping patients *"navigate"* the healthcare system.[376(p2850),377] An Organisation for Economic Co-operation and Development (OECD) report in 2007 identified that primary care systems would need to adapt to meet the increasing demands of those living with chronic conditions, and recommended the introduction of non-medical care co-ordinators to better co-ordinate care.[377] Obviously this role would come with a significant resource implication, however for some patients here their cardiac rehabilitation nurse or heart failure nurse already performed some aspects of this function. These clinicians bridged the gaps in care continuity through proactive communication between clinicians in different healthcare organisations. It has been proposed that safety incidents may occur because conditions outstrip the ability of staff to bridge gaps in care;[41] this was indeed true for some patients in this study, for example those who did not receive the correct set of repeat medicines. Some patients here compensated by bridging the gaps themselves, demonstrating enhanced resilience in the medicines management system, which is discussed in more detail in section 8.5.1. The high betweenness measures of patients in their ego-networks – often viewed as an indicator of 'control' in a network –[296] indicated the high levels of 'control'

they needed to have to manage their medicines effectively. In this context, it is likely that patient 'control' compensates for poor system co-ordination, which is discussed in more detailed in section 8.5. It should be considered, however, that as people age and their conditions deteriorate, they may increasingly lack the ability to both identify and bridge gaps in their care.

Recent USA work developed ten patient-centred priority areas for medicines management, including patients using peers, families and social networks to improve medicines management (patients themselves identified this as a higher priority than researchers and other stakeholders). Other priorities included those relating to prescribing education, enhanced patient knowledge, and the development of tools and systems to evaluate patient-centred medicines plans.[375,378] It is apparent, though, that medicines management outcome measures need to reflect patients' views and values. Adherence is the measure often used to measure the success of medicines management interventions, and more patient-centred outcomes are less commonly measured.[375] Adherence is not a patient-centred outcome because patients' values and preferences may not be aligned with adhering to their medicines instructions. Patient involvement and satisfaction measures, it could be argued, are measures of experience rather than of outcome, yet these are amongst many methods of measuring aspects of patient-centred care.[375,379]

Collins expertly demonstrates the dissonance between how the system records outcomes and how the patient experiences their own health condition.[380] In doing so, he highlights the difficulty in recording patient-centred outcomes: currently the healthcare system values person-centred care for its impact on pre-defined outcomes such as biomedical measures or system measures, i.e., readmissions or appointment keeping, but has no effective way of linking person-centredness to person-centred outcomes. What is required, according to Collins, are Person-Centred-Process-Measures linked to Person-Centred-Outcome-Measures; and measures that take into account the episodic nature of healthcare encounters which deliver outcomes for patients over time. For patients in this study, a person-centred outcome measure might have been their level of orientation about their medicines. Many patients managed multiple medicines for co-morbidities and saw both multiple healthcare professionals and support staff to manage their treatment; their level of confidence and

understanding of their complete medicines set might be a useful indication of the person-centredness of medicines management. Medicines orientation is discussed in more depth in section 8.7.

The next section will discuss the results of this research in the context of systems, patient safety and patient resilience.

8.5 Systems, resilience and patient safety

The work in this thesis has been informed by human factors theory, a systems approach that is capable of effecting safer patient outcomes and understanding where weaknesses in systems create risks for patients. Human factors has been used extensively as a basis to study and improve healthcare systems;[9,25,32,360,381–384] and policy specifically has attempted to make healthcare safer during care transfers with a growing focus on the safety of medicines due to poor co-ordination at handovers of care.[92,385]

Medicines management is a large, important and expensive system within UK healthcare;[74] this research demonstrates, through a wide range of patient-derived data, that this system spans multiple organisations and many HCPs and healthcare support staff but with patients themselves playing a central role in the system. This research also demonstrates that there are multiple contributory factors and defences that respectively pose both risks and protect patients. In doing so, it reflects the premise of Carayon's work looking at a systems engineering model for patient safety that sees the patient as an integral part of the whole system.[383] Carayon et al. developed a model that places the 'person' in the medicines work system who performs tasks and who must interact with others, the physical environment, and organisations to take their medicines at home.[383] 'Task factors' include the number of medicines and doses; 'tools and technologies' are, for example, medicines boxes; 'organisation factors' can be access to medicines. Patients in this study were subject to those contributory factors in self-managing their medicines. The safety incidents in Appendix 6 demonstrate that tools and technologies, such as medicines boxes, confused patients, and organisational factors such as poor management of communication, adversely impacted on patients' access to medicines.

Reactive and proactive approaches to safety management are conceptualised by Hollnagel as Safety 1 and Safety 2.[386] Safety 1, the traditional approach of

learning from failure, is driven by what goes wrong in healthcare to minimise the risk of failures reoccurring. The hypothesis of Safety 1 is that adverse events and events that succeed have different causes. Hollnagel describes this as reactive safety management, because it reacts when things go wrong and takes steps to remedy the system. Alternatively, Safety 2 has a focus on 'what goes right' and how systems can be resilient to variations in practice. For example, how people in systems adapt depending on the working conditions, embracing how people are variable and capable of adapting processes in order to fulfil a task safely. Safety 2 is a proactive practice that attempts to ensure safety through a thorough understanding of systems and people, anticipating where the system has weaknesses and adapting before something goes wrong, rather than afterwards.

For many of the patients in this study the system appeared to work well enough to prevent harm, although not necessarily to proactively optimise benefit from medicines. A focus on what worked well could proactively add to the resilience of the current medicines management system through identifying where systems and the people therein need additional resources to achieve similarly safe outcomes. For example, the following synthesis of the data indicates that:

- Many patients were able to safely self-manage their medicines at home and qualitative semi-structured interviews demonstrated how some developed routines and their own checklists or spreadsheets to help them organise and keep track of their medicines routines. Patient resilience is discussed in more depth in section 8.5.1.
- Interviews also demonstrated that many patients received emotional and practical support after hospital discharge from friends and family, including those people who patients perceived to have heightened knowledge of their medicines.
- Observation data described how some patients benefitted from more patient-centred medicines management at discharge – nursing staff helped them to develop a good understanding of their medicines.
- Ego-network value measures and qualitative interview data showed that some patients obviously valued contact with cardiac rehabilitation or heart failure nurses after their discharge; these staff offered in-depth

- tailored support with patients' treatment and on-going condition management.
- Healthcare professionals often fulfilled medicines management tasks in a way that resulted in safe care, for example there is evidence from interviews that for many patients, discharge medicines information was communicated and acted upon in a timely way, repeat prescriptions were issued and medicines were dispensed. Some patients' denser ego-networks also indicated that some HCPs worked to ensure system gaps did not have too great an impact on patients.

According to Hollnagel, the consequence of the traditional focus of safety on things that go wrong, is a *"creeping lack of attention to things that go right."*[387(p4)] Referred to as *habituation*, characterised as disregarding things that regularly happen, it is possible that because patients often do receive their repeat medicines once back in primary care, there has been little proactive attention on understanding where systems have worked so that good practice can be developed where it is lacking. Indeed, there are positive findings in this thesis. For example, there are robust defences in the system when patients are discharged, including nursing staff using the discharge summary as a checklist when telling patients about their medicines, and the structured processes in place for discharging patients. In short, many aspects of the system function well much of the time. Nevertheless, a substantial minority of patients reported experiencing safety incidents and there are clear opportunities for improvement based on resilience. Although it is an approach that, according to Vincent and Wears clashes with traditional healthcare models that seek to make management decisions through measuring performance;[388] however they also point out that systems can over rely or mistakenly rely on resilience, for example where resources are stretched, where system issues do not represent real challenges, and where system changes actually should be made.

In summary, when considering the medicines management system a balance should be achieved between understanding the causes of safety incidents when they occur and in understanding where systems operate well in order to understand and develop good practice. The following section discusses how patients themselves were able to build resilience into the medicines management system.

8.5.1 Patient resilience

Vincent et al. argue that resilient safety management *"depends on the ability of managers and operators to detect and anticipate dynamic vulnerabilities within the system"*.[389(p27)] Patients can also do this – and it is also important to take into account the potential role of patients' friends and family – in identifying, avoiding and reporting system vulnerabilities and enhancing their strategies to add resilience. Resilience in a system is its ability to continue operating safely in spite of circumstance that may potentially contribute to error, such as unexpected spike in demand, or interruptions during the delivery of care. The data here suggest that patients and their personal contacts play an important role in creating a resilient system, and a deeper understanding of this may contribute towards Safety 2-informed system management. The literature review in Chapter 2 highlighted how research has characterised the patient role in discharge medicines management as one that passively receives care. Research has seldom focussed on patients' own strengths and their often successful self-management of their medicines when they leave hospital and are away from the protective environment of 24-hour hospital care. Furniss et al. outlined seven categories of 'cognitive resilience' – *"the ability to identify and implement strategies that minimise the likelihood or consequences of cognitive slips."*[35(p96)] This framework was later applied to understand how patients developed resilience strategies to minimise the risk of unintentional non-adherence to medicines.[67] The categories are listed in Table 42 below and used to highlight how, as demonstrated in observation and interview data, patients and their personal contacts enhanced discharge medicines management system resilience to avoid patient safety incidents. The patients in this research described or were observed in six of the seven resilience domains, indicating that they and their personal contacts had wide-ranging roles in creating a resilient system that exceeded avoiding unintentional non-adherence, which was the focus of the previous medicines-related application of the framework.[67]

This framework does not account for emotional resilience, which patients in this study described developing through accessing the support of their family and friends. Emotional resilience helped them come to terms with their health condition and enhanced their abilities to continue with their medicines regimens once they had left hospital; in essence providing a protective effect.

Research has explored different impacts of social support on responses and resistance to stress and other physical health outcomes;[390,391] and it has been argued that developing more positive emotions can positively impact on illness recovery.[392] Further work could usefully explore how emotional resilience amongst patients may enhance medicines management systems.

Table 42: Resilience strategies, definitions and examples from this research, from Furniss et al. and Furniss et al.[35,67]

Resilience strategy	Definition	Patient and family examples from this study
Cue creation to support prospective memory	A cue is created as a reminder about something in the future.	Leaving medicines out in a visible place to remember to take them. Setting alarms to remember to take medicines.
Premature completion awareness	Action is taken as a reminder about 'X' after the main goal has been achieved	None discussed or observed
Pre-emptive separation and disambiguation	Things are separated or differentiated so they are not mixed up	Grouping medicines together into the time of day they should be taken. Separating medicines into multi-compartment boxes with differentiating daily medicines doses.
Pre-commitment check	Things are checked before committing to a course of action	Checking the medicines on their repeat prescription after discharge are correct before ordering them. Checking the medicines given to them by community pharmacy before taking them. Keeping hospital packaging and checking new medicines against it. Asking friends and family members and HCPs about possible side effects they perceive.
Managing resource availability	Resources are managed so they are available.	Patients and family members contacting GP surgeries to arrange repeat prescriptions. Carrying around GTN sprays. Patients and family members taking in or telephoning surgeries with information about new and changed medicines. Accessing help to collect medicines from the community pharmacy.
Routine adjustment	Routine is adjusted in response to a threat or an opportunity.	Patients and family members buying compliance aids to help establish a routine with new and changed medicines. Patients and family members creating spreadsheets and checklists to keep track of medicines taken. A family member taking control of supply management and organisation.
Safety reinforcement	Where some safety barrier, procedure or practice is reinforced.	Organising face-to-face contact with an HCP to re-order complicated medicines sets. Patient involvement in reconciliation through giving information about discontinued medicines.

Whilst some patients and their networks worked hard to make medicines management safer, for example in their management of their medicines at home, it remains evident that others are compensating for poorly performing systems that, for example, may fail to accurately perform reconciliation in primary care in a timely way. A recent doctoral study has identified that primary care medicines reconciliation post-hospital is often performed by untrained staff;[393] which falls short of recent medicines optimisation guidelines (NICE 2015).[72] In the context of increasing medicines use in primary care,[74] it is vital that adequate attention is paid to improving the quality and safety of care that patients receive.

8.6 Learning from patient-reported incidents and concerns

Chapter 5 described how many patients in this research alerted their GP practice or pharmacy when there was been a failure in the system that supplied their medicines. As discussed in that chapter, it is probable that most or all of those events went officially unreported. There has been a recent, growing interest in the roles that patients can play in managing their own safety and the tools that may be needed to help them do so. Lawton and Armitage argue that patient reports of patient safety incidents offer new insight into the type and frequency of patient safety incidents over and above those generated through staff reports.[34] For example, open questions, rather than closed, have been assessed as more effective in eliciting patient experiences, such as adverse events;[394] and patients are willing to report events when asked.[33] There is debate, however, about whether patient reports of unsafe care are accurate. For example, a USA study highlighted the differences between the events patients reported as unsafe and the classification of the study's investigators;[395] yet further work demonstrated that patient accounts uncovered more adverse events than medical record review.[66,396] Such data, however, can be hard to collect, for example because patients may feel uncomfortable reporting or challenging the care they have received.[34]

As in previous research, patients in this study were able to recount care experiences that may have caused them harm.[66,395–397] They described them during the interviews focussing on their experiences of managing their medicines and the involvement of other people in doing so. However, it is debatable whether the patients themselves or the staff they interacted with

would have characterised some of their experiences as unsafe and reported them as such. In several instances patients described their experiences as inconvenient or as evidence of poorly organised care, for instance if their GP practice had not updated their medicines list with changes made in hospital. In this study, patients responded to a question asking whether anything had happened that made them more or less confident in their medicines. As previous work has found, the use of this non-technical language (i.e. avoiding terms such as adverse events and medication error) may have been key in helping elicit patient accounts of unsafe care.[394] One question in the semi-structured interview schedule asked patients about the safety of their medicines, and this mostly elicited views of the safety of the medicines products themselves, which they felt were heavily regulated and therefore unlikely to cause them harm. Instead, patient accounts of unsafe care were volunteered in response to a more general, experience-based question. Given the ability of patients here to recount unsafe care when asked about their experiences qualitatively, there may be opportunities to review the way that reporting systems collect information about patient safety incidents using language patients can understand and that can capture their concerns more effectively.

8.7 Medicines orientation

The literature review in Chapter 2 found that studies aiming to understand how staff educate patients about their medicines and how much patients understand their medicines did not take into account the many strategies that may be employed to support desired health behaviours.[152,398] Instead, they focussed on patients' recall of receiving information and their knowledge of their medicines. The thematic analysis of interview data revealed a process that for some patients was different to solely receiving information or developing knowledge. I have used the term *Medicines Orientation* to describe this process and its components are displayed in Figure 57. It was a joint process of the patient developing knowledge about and building confidence in medicines, along with developing particular cognitive and emotional attitudes to their medicines management. Knowledge was developed through receiving or seeking information about medicines, through advice and shared experiences. Confidence was developed through cognitive and emotional attitudes, advice and shared experiences and through receiving information about medicines.

Functionally, medicines orientation led to effective management of medicines in the home.

It is conceptually different from health orientation, which is described as a person's individual motivation to be healthy.[399] Health orientation is based on four indicators: health consciousness; health information orientation; health oriented beliefs; and healthy activities – currently medicines orientation is based on two indicators – knowledge and confidence – and describes how these are built through people's interaction with healthcare professionals and their personal contacts. After leaving hospital, some patients became competent and confident medicines managers and their orientation included adjusting to the new activity involved in medicines taking or their re-adjusting to a changed medicines routine. The different data sources here revealed that medicines orientation was a process that began in hospital and continued through their interactions not only with HCPs – cardiac rehabilitation nurses, community pharmacists, GPs and nurses – but also with their friends and family members who offered advice, shared their experiences and communicated their own attitudes about medicines. This research indicated that HCP involvement in medicines orientation was more effective when a more person-centred approach was adopted, for example the approach used by cardiac rehabilitation nurses. Other research exploring patient-centred medicines activities in a hospital setting found nurses to adopt varying ways of interacting with patients about their medicines and cited time constraints as a barrier to patient-centred medicines activities;[400] interestingly, patients in this study often indicated that whilst some HCPs appeared not to have much time for them, cardiac rehabilitation nurses seemed to dedicate as much time as required to discussing their health and their medicines and ensuring that medicines orientation was as complete as possible. As discussed in section 8.11, there is an opportunity to further explore and refine medicines orientation as a concept through additional research.

Finally, Bodenheimer proposed a self-management education model, drawing comparisons with traditional methods of educating patients, as shown in Figure 58.[401] Traditionally, education is imparted by health professionals through giving disease specific information with the goal of compliance with treatment. Self-management education aims to enhance the patient's confidence to improve

their clinical outcomes through offering problem-solving skills. Education can be provided by those other than a clinician, although the education is still embedded in formal settings.

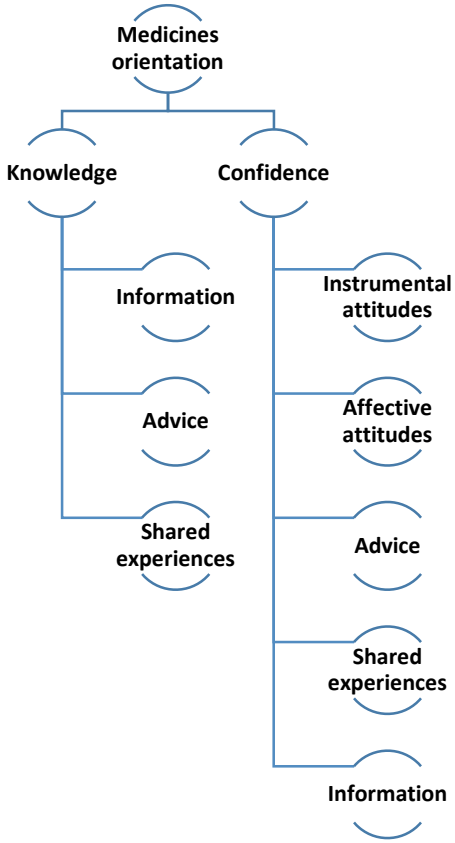

Figure 57: A medicines orientation map, based on qualitative thematic analysis.

Table 43: A comparison of traditional patient education and self-management education, from Bodenheimer.[401]

	Traditional patient education	Self-management education
What is taught?	Information and technical skills about the disease	Skills on how to act on problems
How are problems formulated?	Problems reflect inadequate control of the disease	The patient identifies problems he/she experiences that may or may not be related to the disease
Relation of education to the disease	Education is disease-specific and teaches information and technical skills related to the disease	Education provides problem-solving skills that are relevant to the consequences of chronic conditions in general
What is the theory underlying the education?	Disease-specific knowledge creates behaviour change, which in turn produces better clinical outcomes	Greater patient confidence in his/her capacity to make life-improving changes (self-efficacy) yields better clinical outcomes
What is the goal?	Compliance with the behaviour changes taught to the patient to improve clinical outcomes	Increased self-efficacy to improve clinical outcomes
Who is the educator?	A health professional	A health professional, peer leader, or other patients, often in group settings.

This research has demonstrated that patients orientate themselves towards their medicines in a much more dynamic and fluid way through multiple interactions. In this sense it is more aligned to Pescosolido's Network Episode Model,[245,402] which comprises two internal and three external 'systems' that impact on someone's illness career. This is discussed in more detail in the following section which explores this research in the context of Social Network Analysis.

8.8 Social Network Analysis

Exploring patients' social contexts has provided new insights into the quality of the care patients perceive and the range of professional and personal contacts involved in providing that care. Whilst recent work undertaken at the University of Manchester has used SNA to describe the 'medicines work' undertaken by the patient and others in their social network,[247] this is the first study that has mapped the structures of those networks informed by human factors theory to view a 'system' of medicines management. Using SNA, and specifically an ego-network approach, has facilitated an understanding of the real structure of medicines management viewed from the patient perspective as they experienced it, rather than as it was designed or delivered by HCPs. The research has given novel insight into the degree of patient-centredness in an established system in two distinct geographical areas, which was discussed earlier in section 8.4. Using diaries, interviews and a hierarchical network mapping tool (Figure 14) it has highlighted how patients are at the centre of different compositions of professional and personal contacts and it has allowed an understanding of the types of post-discharge medicines management support some patients benefit from, and of the lack of support and system-access problems experienced by others. The study findings have also given insight into how health policies, such as the move to encourage patients to access the clinical care offered by community pharmacy, are experienced by patients. It has allowed insight into the role patients played in managing those networks of HCPs involved in medicines, affording an understanding of the perceived lack of connectivity amongst HCPs. Finally, the research has aided an understanding that informal communities of personal contacts were leveraged by many patients to gain support in medicines management.

It is universally accepted that people's social networks impact on their health and wellbeing.[250,255] Effects on health arise from perceived and actual social support, social influence, social engagement, social contact and resource access.[250] However, people's use of their social networks in managing their medicines has been less commonly explored or understood. This study has shown the often extensive networks surrounding patients and explored the multiple functions of those networks in providing medicines orientation, health condition management, and medicines support. Importantly, it has shown that patients' medicines management networks have both facilitated and threatened patient safety. Further work might explore in more detail the functional aspects of social networks in patient safety. As a method, SNA has yet to demonstrate its potential value to patient safety research, although there is a small body of work that explores professional networks and the quality and safety of healthcare.[254]

Pescosolido's Network Episode Model describes the impact of social environments on people's illness careers.[245,402] She has explained that SNA *"puts human face on issues of access, barriers, intervention, by conceptualizing these as actions of individuals",*[403] and it also gives context to the human interactions that comprise the care patients receive. She criticises traditional models that have been used to explain health behaviour, such as the Health Belief Model[404] and the Theory of Planned Behaviour,[405] for their inability to explain phenomena such as delay in seeking help, or compliance with treatment. Instead, it is people's networks that connect them to help, care and resources. In most recent version of the Network Episode Model, health choices and illness careers are affected by internal and external systems. Internal systems are genetics and biology; and the external systems are personal connections, health organisations and community. In more recent work Pescosolido argued that a SNA approach offers an ideal mechanism for intervention through understanding the social environments that, for example, create a supportive home, a helpful community or a caring or effective organisation.[402] Healthcare policies, for example, may be well intentioned, but the HCP interpretation and resultant practice in a real-world setting may not reflect the spirit or the content of the policy. Conversely policies may be ineffective and it is crucial to understand these differences. The Network

Episode Model presents the treatment system as a changing network of healthcare providers and different organisations that people interact with, which change according to people's health changes and resource availability. Importantly, a network approach and specifically the Network Episode Model, "*allows us to unpack what happens to people when they go for treatment, and to think about how their experiences effect whether they stay in treatment, take their medications, get better.*"[406(p437)] This research has demonstrated that people's health and treatment is experienced through social ties, either through personal ties that support and facilitate recovery and access to treatment, or through the social, episodic context in which people experience healthcare systems.

Finally, there is a clear opportunity for SNA to explore and understand more about people's behaviours around their medicines. Other research into health behaviours have studied peer-effects on dieting behaviour;[407] weight-loss interventions targeting peer groups;[408,409] smoking behaviours;[410] substance use;[411] and the spread of obesity.[412] The obesity study described how obesity spread within populations – the chances of someone becoming obese were influenced by whether their social contacts also became obese. The study explained that people did not become obese because their friends and family were obese, rather friends and family members became obese concurrently. Given these applications of SNA, it would be both interesting and plausible to design research to understand if peer-group interventions would yield positive effects, for example on attending a medicines use review, or perhaps on reporting a patient safety concern. There is evidence that network-based interventions have been effective in changing behaviour;[413,414] and Smith and Christakis assert that *"the cumulative impact of a therapeutic or preventative intervention is thus the sum of the direct health outcome in the focal individual plus the collateral health outcomes in those to whom he/she is socially connected"*.[250(p419)]

8.9 Critique of the study

Many of the limitations of the research outlined in this thesis were discussed in Chapter 3 and throughout the results Chapters 4–7. Here, an overview of the most important limitations will afford some broader context for readers to consider when evaluating the various approaches as a whole.

The necessity to conduct a relatively small sample study to determine the extent of patients' ego-networks through qualitative methods meant that, whilst saturation occurred, the quantitative aspects of the mixed methods research cannot in any statistical sense be generalised. Indeed, this is why the statistical modelling undertaken in Chapter 7 was designed to be exploratory and to aid interpretation, rather than to be statistically inferential. Despite this, the quantitative aspects of the research gave a strong indication of the types of experiences patients had and the range of different demographics achieved in the sample also adds to confidence that the findings are not limited to a narrow group of patients.

This work focussed on only one category of health condition. As discussed in Chapter 3, cardiology was chosen because of its growing prevalence in the population and the impact it has on both patients and the UK healthcare system. Cardiology patients will almost inevitably have changes made to their medicines after a hospital admission. A focus on just one health condition means the work cannot fully represent the patient population and the myriad health conditions people live with, however the research literature reviewed in Chapter 2 indicated that patients with a range of different health conditions share some of the same experiences of the medicines management system. It is therefore likely that conducting the same research with patients with other chronic conditions may uncover similar experiences. Further research across a spectrum of conditions, however, would provide a stronger evidence base.

This study focussed on all patients who left hospital with medicines, rather than those who left hospital with just new or changed medicines, although within the sample very few patients had not had their medicines amended during their inpatient stay. Targeting the sample to only those patients with changed medicines might have given clearer insight into the experiences of those people who may benefit from targeted support with medicines changes or completely new sets of medicines following their discharge. However, the wider focus meant that the study included those patients who may have been struggling to manage their medicines before their hospital admission, which indeed may have precipitated or contributed to their need for acute care. It also afforded an insight into people's established medicines routines in the home and the pattern of interactions about their medicines with HCPs and informal contacts.

8.10 Conclusions

This research has explored the structure, content and function of patients' discharge medicines management ego-networks in two healthcare economies in England. A structured narrative literature review highlighted how studies of patients' experiences of discharge medicines management had not used systems frameworks, despite a quarter of a century of international and UK policy advocating systems approaches in healthcare.

In applying a combined human factors framework and SNA this research has generated novel insights into the composition of the discharge medicines management system. Clearly triangulated data offered evidence about the preparation patients received to use their medicines, related during interviews and complemented by the analysis of the observations made during hospital discharge. Together the data also highlighted the wide variation in post-hospital experiences; uncovered previously 'hidden' parts of the system; found ways that patients and their personal network members bridge gaps in their care through developing resilience strategies; and highlighted how the formal system places patients at risk and in some instances failed to enhance patient resilience through a lack of preparation to enable patients to effectively self-manage medicines. It has described the healthcare professionals and healthcare support staff who, along with patients and their informal networks, comprise the discharge medicines management system and it has demonstrated considerable variation in the structure of medicines management experienced by patients. This research has highlighted how patients experience a loosely connected network of professionals performing medicines management functions. Patients perceived little contact between professionals engaged in managing their medicines and the study showed that patients experienced significant gaps in the continuity of their care.

8.11 Recommendations for future research

The results of this research have raised several issues that merit further exploration. The optimum time for providing medicines support after hospital discharge would benefit from further exploration. The observation study showed that for some patients the focus of their last day in hospital was about getting home, rather than absorbing new information. This study found wide variation in what patients were told about their medicines when they left hospital and each

individual had different needs associated with developing their capabilities around their medicines. Further research should explore patients' medicines support needs in more depth to build a personalised framework that considers the optimal time for provision of medicines orientation. This should be undertaken in a way that fully involves patients, for example through experience-based co-design.[415]

This research constructed a measure of patients' discharge medicines management experiences. Future research could refine that measure with the input or co-design of patients to explore how it could be further developed as a specific, patient-centred outcome measure. This work should begin qualitatively to explore patients' views of the importance of the questionnaire items and how well they are able to capture their experiences of the complex medicines management system.

In addition, the study found that patients with multiple morbidities had many different healthcare professionals involved in prescribing, monitoring and adjusting their medicines. Currently, information from different HCPs about patients' medicines are fed through to GP practices. As the number of people living with multiple chronic conditions who require multiple specialist inputs increases, it will be crucial to pay attention to the role of GP practices in proactively managing this network. Further research should explore the barriers and facilitators to GP practices' safe and proactive management of patients' medicines information. This research should be informed by human factors and should also take into account the patient's role in managing information about their medicines.

As described in section 8.7, the process of medicines orientation would benefit from further research to develop a deeper understanding of how patients develop knowledge of and confidence in their medicines. This should be done qualitatively in the first instance, following patients with newly prescribed medicines over a period of time, collecting data regularly, to understand the drivers of developing understanding, shifting attitudes and growing confidence.

Section 8.8 described how network-based peer interventions can positively impact of health behaviours. Further research to develop a peer-group medicines management intervention using a social network analysis framework

could explore whether peer-group interventions might yield positive effects on patient safety, medicines management and on patient-centred outcomes. Areas for research might include medicines orientation, attending a MUR, or reporting a patient safety concern.

Finally, research exploring possible links between patient-centredness and patient safety would usefully contribute towards understanding how these two important aspects of healthcare can be further and more effectively integrated.

8.12 Recommendations for policy

There are clear implications for policymakers arising from the results of this research. In the first instance, and perhaps most importantly, there should be an increased drive to encourage patient reporting of medicines-related patient safety incidents following hospital discharge. Before this happens, patients need to know what a patient safety incident is, and why reporting is important, so as to help patients recognise situations where they have been at risk of preventable harm. It is crucial, however, that patients do not perceive that the quality of their care will be adversely impacted. Secondly, the NHS should act on information from this and other research and develop the role of a transfer manager to work with patients, their families and clinicians and to support patients in their post-discharge condition management. This should be a patient-centred role and policy-makers could usefully explore the transferability of the cardiac rehabilitation model. There might also be a review of the way GP practices manage the polypharmacy of patients with multiple morbidities and whether they take a proactive role in coordinating and overseeing the input of specialist clinicians from other organisations.

Policy should draw attention to how medicines management systems that perform well achieve good quality and safe care for their patients. Further exploration of patients' medicines management resilience strategies might enable HCPs to share those strategies in other patients. Patients could also be encouraged to share their strategies within peer networks.

Changes need to be made to how patients are introduced to the MUR; for example, by referral from the hospital or by their GP which would aid patient understanding of its importance and its purpose, enhance patient confidence in it and give them the time to prepare for what is potentially a key aspect of their

care. Moving the review from the high street into a more clinical environment, such as a GP practice, may also enhance patient perceptions of its value. The content of the MUR consultation should also be re-visited so that patients receive tailored, practical help in organising medicines or creating checklists. Some patients in this research had devolved responsibility for their medicines to a family member, so therefore including a family member who manages the patient's medicines may also enhance the MUR's outcomes. Redesigning the service and how it is communicated based on a behavioural insights framework, such as EAST,[364] might positively impact on its uptake.

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Appendix 1 – Literature quality assessment table

Key:

1	Explicit theoretical framework	9	Statistical assessment or reliability and validity of tools
2	Statement of aims/objectives in the main body	10	Fit between research question and tools
3	Clear description of research setting	11	Fit between research question and analysis
4	Sample size considered in terms of analysis	12	Justification for analysis
5	Representative sample	13	Assessment of reliability of process
6	Description of data collection procedure	14	User involvement in design
7	Rationale for data collection tools	15	Strengths and limitations discussed
8	Detailed recruitment data		

Author / year	1	2	3	4	5	6	7	8	9	10	11	12	13	14	15
Adeponle et al. 2009	0	3	2	0	2	3	2	3	0	2	1	1	0	0	1
Ahmad et al. 2012	0	2	1	0	2	1	2	1	1	2	2	1	/	0	2
Ahmad et al. 2014	0	3	2	0	2	2	2	3	1	2	1	2	/	0	2
Ali et al. 2009	0	2	3	0	3	3	1	3	0	2	2	1	/	0	3
Arnetz et al. 2010	0	2	2	0	2	3	3	3	2	0	2	2	/	0	3
Attebring et al. 2005	0	2	3	0	3	2	2	2	/	3	3	3	3	0	1
Bagge et al. 2014	0	3	3	0	3	2	2	3	/	1	3	3	3	0	1
Beers et al. 1992	0	2	3	0	1	3	0	1	1	0	1	0	/	1	1
Bennett et al. 2014	0	3	3	0	3	1	2	1	2	2	2	1	/	0	2
Blennerhasset and Hilbers, 2011	0	2	1	0	2	2	1	0	/	2	1	0	0	0	0
Borgsteede et al. 2011	0	2	2	3	2	1	0	2	/	0	2	0	1	0	2
Bremner et al. 2012	0	0	2	2	1	2	0	1	/	2	3	2	2	0	2
Brown, 1995	0	1	2	0	2	2	0	2	0	0	0	0	/	0	0
Burns et al. 1992	0	0	2	0	2	1	0	2	0	0	1	0	0	0	0
Bushnell et al. 2010	0	3	3	0	3	3	3	3	0	3	3	2	/	0	2
Calkins et al. 1997	0	3	2	0	2	3	1	3	0	0	1	1	/	0	3

Author / year	1	2	3	4	5	6	7	8	9	10	11	12	13	14	15
Chau et al. 2011	0	2	3	2	2	3	1	2	0	0	3	3	/	0	3
Cochrane et al. 1992	0	2	3	0	2	3	0	1	0	0	2	0	/	0	0
Coleman et a. 2005	0	3	3	0	2	1	3	1	2	0	2	1	/	0	1
Conn et al. 1991	0	2	3	0	2	3	3	3	0	3	3	1	/	0	1
Conn et al. 1992	0	2	3	0	2	2	1	0	0	3	1	0	/	0	0
Decker et al. 2008	2	2	3	0	2	2	3	2	/	2	3	2	3	0	2
Ehrenreich et al. 2012	1	3	3	0	1	3	2	3	0	1	2	2	/	0	3
Eijsbroek et al. 2013	0	3	3	0	2	3	3	1	/	2	3	2	1	0	2
Enguidanos and Brumley, 2005	*0*	*2*	*3*	*1*	*3*	*1*	*0*	*2*	*0*	*0*	*2*	*0*	*/*	*0*	*0*
Forster et al. 2005	*0*	*2*	*3*	*0*	*3*	*3*	*2*	*2*	*2*	*0*	*2*	*3*	*/*	*0*	*2*
Forster et al. 2004	0	2	3	0	3	3	1	3	2	0	2	1	/	0	1
Forster et al. 2003	0	2	3	0	3	2	2	2	0	0	2	1	/	0	3
Garavalia et al. 2011	0	2	3	3	2	2	1	2	/	2	2	1	3	0	2
Gray et al. 1999	0	3	3	2	2	3	1	3	2	0	2	1	/	0	3
Gray et al. 2001	0	2	3	2	2	3	1	3	2	0	3	1	/	0	3
Glintborg et al. 2007	0	2	3	0	2	3	2	3	1	1	0	2	/	0	2
Graham and Kunkle, 1996	0	3	3	0	2	2	1	2	0	3	2	0	/	0	2
Hain et al, 2012	0	1	2	0	2	3	3	1	2	1	1	1	/	0	1
Johnson et al. 2010	0	2	2	0	1	3	1	3	0	1	0	1	/	0	3
Kerzman et al. 2004	0	3	3	2	2	2	1	2	0	0	2	0	/	0	3
Kimmel et al. 2010	0	1	3	0	2	3	2	3	0	0	2	0	/	0	2
King et al. 1998.	0	3	3	0	2	2	3	1	1	3	2	2	0	1	3
Knight et al. 2011	0	3	3	0	2	3	1	3	/	2	3	0	0	0	1
Kripalani et al. 2008a	0	2	2	0	2	3	3	3	3	0	2	2	/	0	3
Kripalani et al., 2008b	0	2	3	0	5	1	1	3	0	1	3	1	/	0	3
Krishnan et al. 2004	0	2	3	0	1	2	1	3	0	1	2	1	/	0	2
Leegaard And Fagermoen, 2007	0	2	3	0	1	2	3	2	/	2	2	2	2	0	3
Lindquist et al. 2011	0	2	2	0	2	3	1	3	0	2	2	2	/	0	2
Maniaci et al. 2008	0	2	2	0	2	3	1	3	0	0	1	1	/	0	2
Makaryus and Friedman, 2005	0	1	2	0	1	1	0	1	0	0	1	0	/	0	0
Manuel et al. 2011	0	0	3	0	2	2	0	1	/	0	2	1	2	0	1

Author / year	1	2	3	4	5	6	7	8	9	10	11	12	13	14	15
Mansur et al. 2008	0	3	2	0	2	2	0	2	1	0	3	2	/	0	2
Mansur et al. 2009	0	3	2	0	2	3	3	3	0	3	2	1	/	0	2
Martens 1998	0	2	3	0	3	3	2	2	/	0	0	0	0	0	0
Marusic et al. 2014	0	2	3	0	2	3	0	2	0	2	2	2	0	0	3
Melloni et al. 2009	0	2	3	0	3	3	2	3	0	3	2	2	/	0	2
Micheli et al. 2007	0	3	3	0	3	3	1	2	0	0	2	3	/	1	2
Mistiaen et al. 1997	0	0	3	0	2	3	3	3	3	3	2	0	/	1	0
Mulhem et al. 2013	0	1	1	1	1	2	0	3	0	0	1	1	/	0	1
Nikolaus et al. 1996	0	3	3	0	2	3	3	2	0	0	1	0	/	0	1
Olfson et al. 2000	0	1	3	0	3	3	2	3	0	3	1	1	/	0	0
Pasina et al. 2014	0	1	3	0	2	2	2	3	0	3	2	2	/	0	3
Paulino et al. 2004	0	3	3	0	2	3	0	3	0	3	3	1	/	0	3
Rushworth et al. 2012	0	2	2	2	2	2	3	2	/	2	3	2	2	1	3
Sexton and Brown, 1999	0	3	3	0	1	2	2	1	0	1	1	0	/	0	0
Souter et al. 2014	0	3	3	3	3	3	3	3	/	3	2	0	2	0	3
Stafford et al. 2012	0	3	3	0	1	2	2	2	/	0	3	2	2	0	3
Stange et al. 2012	0	1	2	0	2	3	2	2	1	2	3	2	/	0	1
Stewart and Pearson, 1999	0	3	2	0	2	3	1	1	0	0	2	0	/	0	3
Tarantino et al. 2010	1	3	2	0	2	3	2	2	0	2	2	1	/	0	0
Toren et al. 2006	0	3	2	0	2	3	3	3	0	2	3	0	/	0	3
Ulfvarson et al. 2005	0	2	3	0	3	3	2	2	0	2	2	1	/	0	2
Ulfvarson et al. 2006	0	2	3	0	2	3	3	1	0	2	2	2	/	2	0
West et al. 2010	1	2	2	0	1	3	2	3	0	0	0	2	/	0	1
White et al. 2010	0	3	3	3	2	2	2	2	/	0	2	0	3	0	2
Ziaeian, B et al. 2012	0	1	3	0	3	3	1	3	0	0	2	2	/	0	3
Total	**5**	**153**	**188**	**26**	**152**	**177**	**115**	**158**	**29**	**87**	**137**	**83**	**29**	**7**	**127**

Appendix 2 – Data collection tools

A Patient information leaflet

INVITATION TO JOIN A RESEACH PROJECT

A study of communication about medicines after discharge from hospital

You are being invited to take part in a research study.

Before you decide whether to take part, it is important for you to understand why the research is being done and what is involved. Please take time to read the following information carefully and discuss it with friends or relatives if you wish. You are entirely free to decide whether or not to take part in this study.

Your decision about taking part will not affect the standard of care you receive.

If there is anything that is not clear, or if you would like more information, please speak to Beth Fylan – the study co-ordinator – who will be available on the ward to answer your questions.

The study will involve you keeping a record of who you contact and who contacts you about your medicines from the time you are discharged from hospital until just after you receive your first repeat prescription from your GP surgery. We also would like you take part in a 30-45 minute interview either at the hospital, at your home or in a place of your choice that is convenient to you.

PATIENT INFORMATION LEAFLET

A study of communication about medicines after discharge from hospital

- We would like to invite you to take part in our research study.

- Before you decide we would like you to understand why the research is being done and what it would involve for you. One of our team will go through the information sheet with you and answer any questions you have. We'd suggest this should take about 15 minutes.

- Talk to others about the study if you wish.

- Ask us if there is anything that is not clear.

About the study

The main purpose of this study is to find out who you contact and who contacts you about your medicines once you are discharged from hospital. We want to find out more about how well the healthcare team tells you about your medicines, who, if anyone, helps you understand how to take your medicines and whether you are given enough help and information to take your medicines as they should be taken. We also want to know which healthcare professionals – for example GPs, nurses, pharmacists – you have contact with about your medicines as well as any other people you talk to about your medicines.

Why have I been chosen?

You have been in hospital being treated for a heart condition for which a combination of medicines is known to benefit your heart and improve your health and wellbeing. It is important that you receive good information about your medicines, that you understand them, and that others involved in your care – your consultant, your nurse, your GP and your community pharmacist – communicate well with each other and with you about them.

Do I have to take part?

No, it is up to you to decide to join the study. We will explain the study and go through this information sheet with you. If you agree to take part, we will then ask you to sign a consent form. You are free to change your mind at any time, without giving a reason. This would not affect the standard of care you receive and you will not be treated any differently whether you decide to take part or not.

How do I take part?

If you might like to take part in this study you should complete the Study Sign-up form accompanying this leaflet, sign the Agreement to Participate form and return them in the envelope provided to the ward reception area or to Beth Fylan, the study co-ordinator, who will be available on the ward. We will use your answers on the questionnaire to check that you are suitable for the study. If you are suitable, we will give you a short contact sheet to complete from the day of your discharge from hospital for approximately six weeks. We will also phone you within a week of your discharge to see how you are getting on filling in your contact sheet and to see if you have any questions about it.

There is an example of the type of information we want you to record attached to this leaflet.

What am I being asked to do?

We want you to keep a record of who you have contact with about your medicines from the time you are discharged from hospital and receive your discharge medication until just after your receive your first repeat prescription from your GP. On this sheet we want you to make a note of when you contact other people about your medicines and when they contact you. This contact might be a letter from the hospital, a conversation with a pharmacist, or a conversation with your GP or nurse. We also want you to note down any times you ask friends or family for information or help with your medicines or if anyone offers you advice or asks you questions about your medicines. We hope that you will fill in the contact sheet every evening.

After six weeks we will ask you to take part in an interview with one researcher that will last around 30-45 minutes, during which we will ask you about your diary and about your views about the different roles people and professionals play in helping you with your medicines. We will also ask you to answer questions about what you think about your medicines. The interview will be with one person and it will be audio recorded with your permission.
The interview may be held at the Cardiac Rehab Clinic, in your own home, or in another place of your choice – whichever you prefer. There are no right or wrong answers – we are just interested in your experiences and what you think.

Will the information I give be kept confidential?

Nobody – including your healthcare team – will be able to find out what individual people have written down or said. All information which you give us will be kept strictly confidential, and any information will have your name removed before it is stored electronically. With your permission, we will audio record interviews but your name will not kept with the transcript or the recording of your interview. Data you give us will be stored securely at the University of Bradford and only members of the research team will have access to it. All the data you give us will be stored for three years and then destroyed.

The things that people talk about during interviews and write in their contact sheets will be summarised and included in a report, but no information will be included that would allow anyone to find out what individual people have said.

What are the benefits of taking part?

The information we get from this study may help the way that other patients are told about their medicines and it may prevent them from experiencing problems in the future. It may prevent people from experiencing problems with medicines or from not understanding their medicines well enough.

What are the drawbacks of taking part?

You will need to regularly fill in your contact sheet for approximately six weeks and also spare the time to be interviewed about your experiences.

What happens at the end of the study?

Your part in the study will end with the interview approximately six weeks after you leave hospital. We will then take the information you and others have given us and use it to see if improvements can be made to the way people communicate with patients. The information will be used to write a report and we will also publish the study results in a professional journal, but you will not be identified in any published report or journal article.

What if I decide during the research that I don't want to take part any more?

That's ok – just tell me that you don't want to talk any more. You don't have to give a reason.

What if I have worries about my medicines?

If you have worries about your medicines whilst you are taking part in the study you should talk to your doctor, nurse or pharmacist. As researchers we cannot give you medical advice, but it is important that you speak to a qualified person if you are worried about your medicines for any reason.

Study organisation

This study has been designed coordinated and funded by researchers at the University of Bradford. The study design has been reviewed and agreed by independent Research Ethics Committees.

What if I have questions about the study?

If there's anything you're not sure about, or if you have any questions, you can ask Beth Fylan who will be available on the ward or by telephone on 07866 678764 or email e.m.m.fylan@bradford.ac.uk

What if I have a complaint about the study?

If you want to make a complaint at any point about any aspect of the study you can contact Professor Alison Blenkinsopp (01274 234290) or Professor Gerry Armitage (01274 236474) at the University of Bradford.

Thank you for considering taking part.

B Patient consent form

Do you consent to take part in the study?

A study of communication about medicines after discharge from hospital

Please read each of the following points and tick the box if you agree. Just ask if there is anything you don't understand or you are unsure about.

1. I confirm that I have had the opportunity to ask questions about the study and, if I asked, my questions were answered fully……. ☐
2. I have read and understand the information sheet version [….] date [……] …….. ☐
3. I understand that participation is voluntary and I am free to withdraw at any time without giving and reason, and without my medical care being affected…… ☐
4. I understand that any data about me will be anonymised, confidential, and kept securely. I give permission for members of the research team to have access to my anonymised responses…….. ☐
5. I agree to take part in the above study……..... ☐

Your name

(print)……..

Your signature ……..

Date ……..

Researcher's signature ……

Date ……

Office use: Patient ID number for study: _____

One copy to researcher and one copy to the patient

C Staff information leaflet

Observation of communication about medicines at discharge – Information for staff

You are being invited to take part in a research study. Before you decide whether or not you would like to participate it is important that you understand why the research is being carried out and what will be involved if you decide to participate. The following information explains the purpose of the study and other relevant information. Please take time to read it carefully and discuss it with others if you wish. If there is anything that is not clear, or if you would like more information, please do not hesitate to ask.

Who is conducting the research?

The research is being conducted by Beth Fylan Gwynn from the University of Bradford. Telephone Number 07866 678764 or e-mail e.m.m.fylan@bradford.ac.uk

What is the purpose of the study?

The aim of the study is to gain understanding of the ways in which information about medicines is communicated to patients.

Who is being invited to take part in the study?

You have been invited to take part in this study as you carry out one or more aspects of medicines management as part of your everyday role and you are caring for a patient who has agreed to participate in the study.

What will be involved if I take part?

The study will be explained and you will have the opportunity to ask any questions. You will then be asked to sign a consent form to show you have agreed to take part. You will be able to keep a copy of this sheet and the consent form. If you consent to take part, you will be observed whilst you are communicating with patients about their discharge 'take-home' medicines. The researcher will take notes during the observation. The researcher will ensure that the shadowing does not interrupt patient care.

Do I have to take part?

No. You can decide whether or not you want to take part. If, however, you do decide to take part, but then decide that you no longer want to be part of the study, you are free to withdraw at any time, without giving a reason.

What happens to the information collected during the study?

Your identity and any personal information that may be required to communicate with you will be completely confidential and known only to the researcher. No record will be kept of actual names and locations. The information obtained will remain confidential and stored within a locked filing cabinet. Data will be kept safely and you will not be identified in any report or publication.

What are the benefits of taking part?

By taking part in this research, you will be providing valuable information regarding medicines management. It is hoped that this information can be used to improve the process of medicines management, reduce medication errors, and improve patient safety.

Who has reviewed the study?

This study has been reviewed and approved by a team of research supervisors at the University of Bradford, and the Yorkshire and the Humber (Bradford) Research Ethics Committee.

If you have any further questions?

If you would like more information about the study you can contact Beth Fylan Gwynn, School of Pharmacy, University of Bradford, Bradford, BD7 1DP. Telephone Number 07866 678764 or e-mail e.m.m.fylan@bradford.ac.uk.

What will happen to the research when it is finished?

The research will be written up for publication in academic journals so that others can learn from the findings. The data will also be submitted as part of a doctoral thesis (PhD) in Pharmacy. If you would like a copy of the findings you can contact Beth Fylan Gwynn using the contact details above.

What should I do if I would like to complain about the study?

If you are unhappy about any aspect of the study, please contact myself in the first instance. Alternatively you can contact Professor Alison Blenkinsopp at the University of Bradford on 01274 234698 or professor Gerry Armitage at the University of Bradford on 01274 236474.

Thank you for taking time to read the above information.

D Staff consent form

Observation of communication about medicines at discharge

Please tick the box

I have read and understand the information sheet dated..... (version.....) for the above study. I have had the opportunity to consider the information, ask questions and have had these answered fully. ☐

I understand that my participation is voluntary and that I am free to withdraw at any time, without giving any reason. ☐

I understand that my data will be anonymised, confidential, and kept securely. I give permission for members of the research team to have access to my anonymised responses ☐

☐

Your name _____

Date _____

Signature _____

Name of Researcher _____

Date _____

Signature _____

1 copy to the participant 1 copy to the researcher

E Discharge observation contact sheet

Patient ID:_____ Site:_____ Date:_____Time: _____

Observation number	Staff type[1]	Purposes[2]	Understanding check? (Y/N)	Question? (Y/N)	Researcher notes
1	**N1**	**P; W; D; Dis; N**	**N**	**Y**	
2					

[1] *Staff types:* ***HCA1*** *(Health care assistant 1);* ***CD1*** *(Consultant 1);* ***D1*** *(Doctor 1);* ***S1*** *(Sister 1);* ***N1*** *(Nurse1);* ***P1*** *(Pharmacist 1);* ***PT1*** *(Pharmacy Technician 1);* ***O1*** *(Other 1)*

[2] *Purposes:* ***P*** *(purpose of the medicines;* ***N*** *(new medicines);* ***Dis*** *(Discontinued medicines)* ***S*** *(Side effects);* ***D*** *(dose information);* ***T*** *(timing information);* ***HC*** *(hospital communication with primary care);* ***R*** *(obtaining repeat medicines in primary care);* ***U*** *(using pre-admission supplies of medicines);* ***W*** *(giving written take-home information);* ***OTC*** *(over-the-counter drugs to avoid);* ***F*** *(foods / drinks to avoid).*

F Medicines contact diary sheet

Please keep a brief record in the table below of the contacts you make or receive concerning your medicines. Please give as much detail as possible and try to differentiate between people – for example you may over the course of the next six weeks speak to more than one pharmacist or GP so try to capture at least their initials or first name if possible.

Date	**People I contacted**	**People who contacted me**	**Role / relationship to me**	**Contact type**	**What happened**
15/09/13	*Dave*		*Son*	*Face-to-face*	*Asked me if I needed help organising my medicines packages*
16/09/13	*No contact*	*No contact*			
17/09/13	*Sainsbury's pharmacy – Pharmacist*		*Pharmacist*	*I visited in person*	*I asked for indigestion tablets. Advised to take brand X*

G Patient interview schedule

Briefing. Permission to record.

Thank you for completing your contact diary sheet. I have a few questions I'd like to ask you about what you have written down. First though, I'd like to ask you some questions about your experiences with your medicines since leaving hospital. There are no right or wrong answers – I am interested in your opinions and experiences.

1. Tell me about your experiences with your medicines since leaving hospital.
When you left hospital were you given a supply of medicines to take home with you? (Probe – who, when, where, number of days' supply of meds)

Did someone at the hospital give you a list of your medicines? Who?

Did someone at the hospital speak to you about your medicines before you went home? (Probe – who? Nurse / doctor /pharmacy technician, when and where did this happen? What was said? Were you given any written information? Did you ask any questions? Why / why not?) How much information were you given about the possible side effects from your medicines?

How easy or difficult was it to understand the information you were given?

How different were the medicines you left hospital with to those you took before you were admitted? Were any of them new? Did anyone explain the changes to you? Did you know if you needed to use any of the supply of medicines you had before you went into hospital?

How many different medicines do you now take? What are they for? At what times of day do you take them?

How easy or difficult has it been to take your medicines as instructed? Why is this the case?

When you left hospital was there anything you were unsure about or any questions you had about your medicines?

When you left hospital were you able to get out and about easily or was this difficult for you?

2. How confident are you in your medicines?

Are you taking them? To what extent do you feel they are effective? Do you feel safe taking them? Why / why not? Do you feel like they help your condition(s)?

Has anything happened since you left hospital to make you more or less confident in your medicines?

How much do you understand how to take your medicines? And why you are taking them?

3. Now I'd like to discuss your diary sheet.

Could you tell me about how you think each person in your diary helped you manage your medicines after you left hospital? (take each person in turn)

How positive or negative is their input? How does the contact you have with them make you feel? Confident? Confused? Reassured? Cared for? Something else?

What input does your GP have? How about the community pharmacy? Other healthcare professionals?

What input do your friends and family have?

How about other sources of information – the internet, leaflets? Anything else? How useful are

they to you?

How have each of these contacts influenced how you take your medicines? And how you feel about your medicines?

Why did you choose to discuss your medicines with this person?

How easy or difficult are they to contact? How helpful or unhelpful do you find them? How useful do you find the information, help or advice you get from them? How much time do you think they have for you?

4. Now I'd like you to look at this personal network diagram

How would you rate the contacts involved in your medicines? (There will be a diagram with concentric circles and patients will indicate where this person sits – the closer to the centre the more they value them).

Why do these people play a bigger role than others in your medicines? And why are these people not so important?

How much do you feel each of these people listen to you? And understand you?

Have your medicines needs been met? How could the care you receive from professionals relating to your medicines be improved?

How much do you think each of the contacts in your diary communicate with each other about your medicines?

How much do you have to co-ordinate the input of healthcare professionals into your medicines?

How joined up do you think the professional medicines care you get is? Do you think professionals work together to make sure your medicines are right for you?

Thank you. Debrief. Do you have any questions?

If you have any questions or concerns about your medicines you should contact a healthcare professional to discuss them. This could be your GP, your community pharmacist, or a community nurse. Contact details.

H Medicines experience survey

Many thanks for agreeing to complete this short survey. Your answers to these questions will be kept confidential. There are no right or wrong answers – we are only interested in what you think.

How much to you agree or disagree with the following ten statements? Tick one box for each question to tell us what you think.

	Strongly disagree	**Slightly disagree**	**Not sure**	**Slightly agree**	**Strongly agree**
When I left the hospital, I clearly understood the purpose for taking each of my medicines					
I am confident I can take my medicines as instructed					
It is easy for me to ask my community pharmacist questions about my medicines					
When I left the hospital, I clearly understood how to take each of my medicines					
It is easy for me to understand the instructions I was given for my medicines					
It is easy for me to ask my GP questions about my medicines					
I currently understand the purpose for taking each of my medicines					
The healthcare team work together to support me in managing my medicines					
It is easy for me to get all the information I need about my medicines					

Many thanks!

Patient ID: _____

I About you survey

About you

Age (in years): _____

Gender: ☐ Male ☐ Female

Home address:

_____

_____

Postcode: _____

Contact email address (if you have one): _____ _____

Home phone number: _____

Mobile number (if you have one): _____

GP name: _____

GP surgery: _____

Which community pharmacy do you usually use?

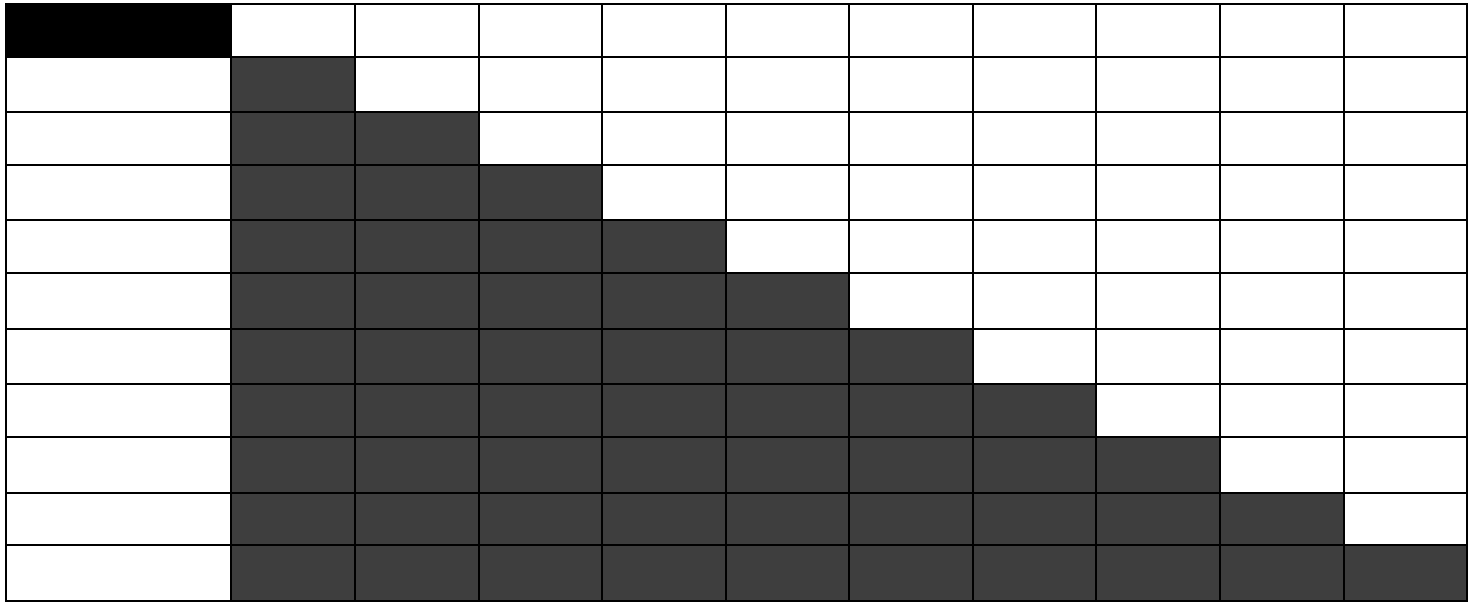
_____

Thank you!

[Patient ID number [for office use only]_____]

J Network grid

Patient ID_____



Appendix 3 – Ego-networks for all patients

Thicker lines between ego and alters indicate more valued ties.

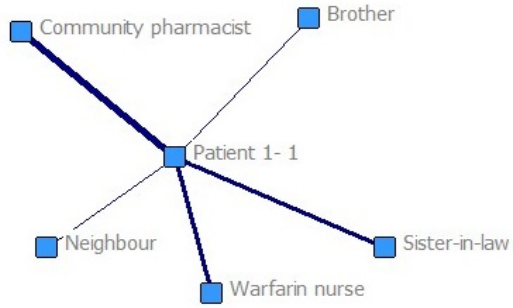


Figure 58: Sociogram of ego-network of Patient 1.1

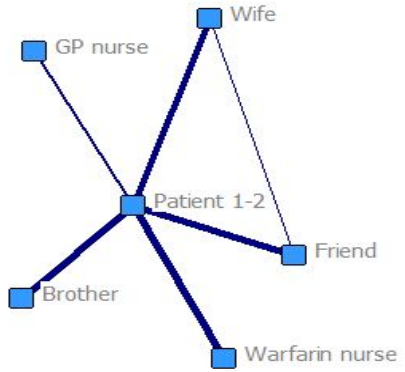


Figure 59: Sociogram of the ego-network of Patient 1.2

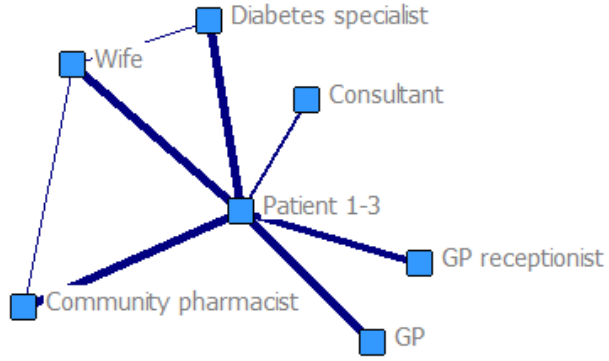


Figure 60: Sociogram of ego-network of Patient 1.3

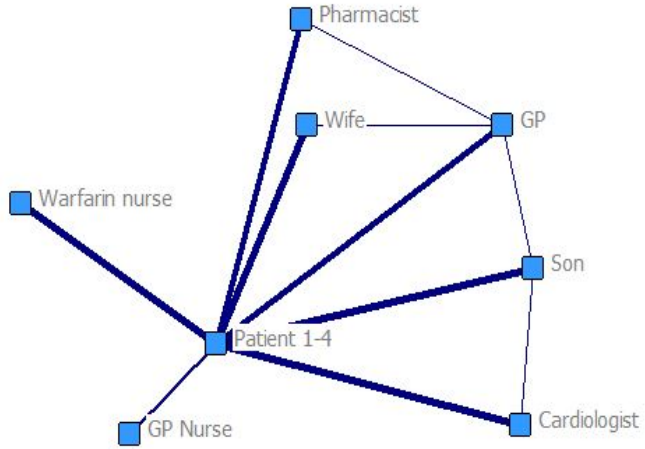


Figure 61: Sociogram of the ego-network of Patient 1.4

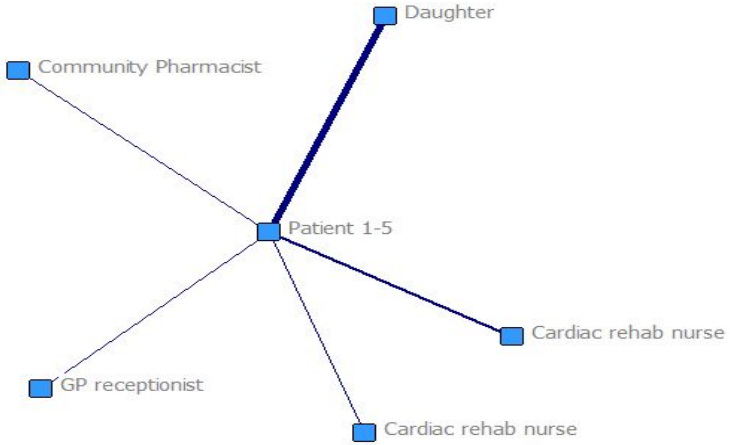


Figure 62: Sociogram of the ego-network of Patient 1.5

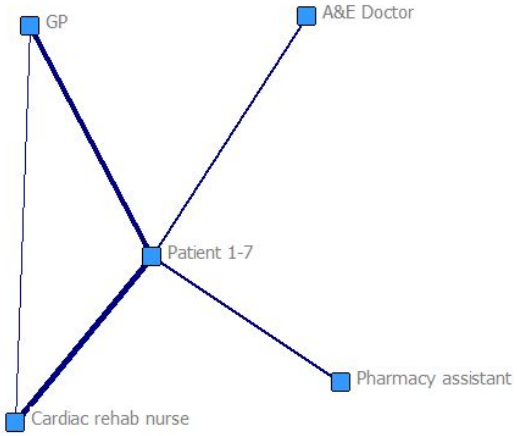


Figure 63: Sociogram of the ego-network of Patient 1.7

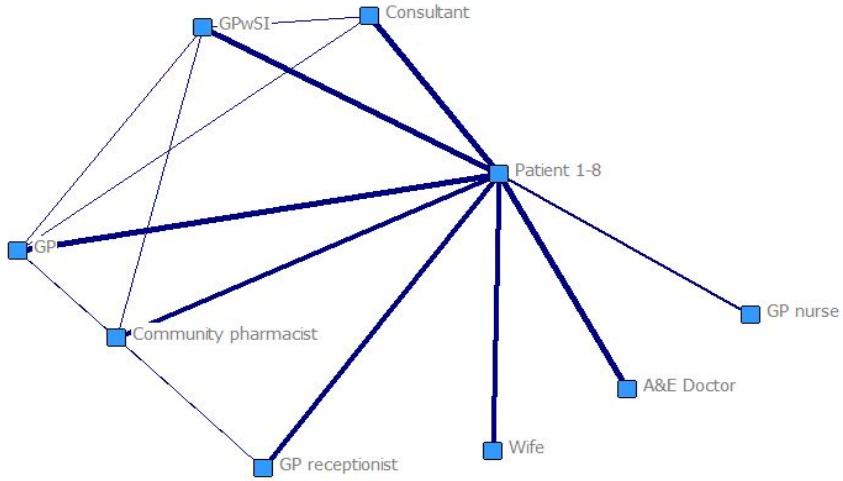


Figure 64: Sociogram of ego-network of Patient 1.8

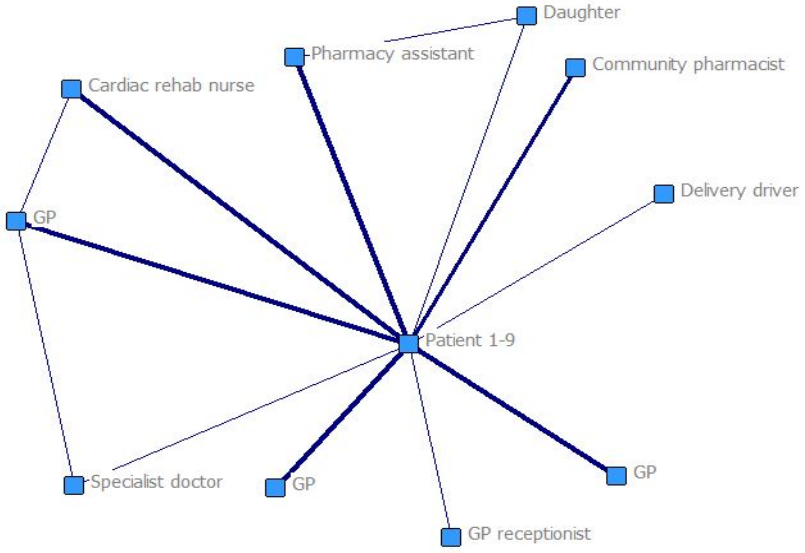


Figure 65: Sociogram of the ego-network of Patient 1.9

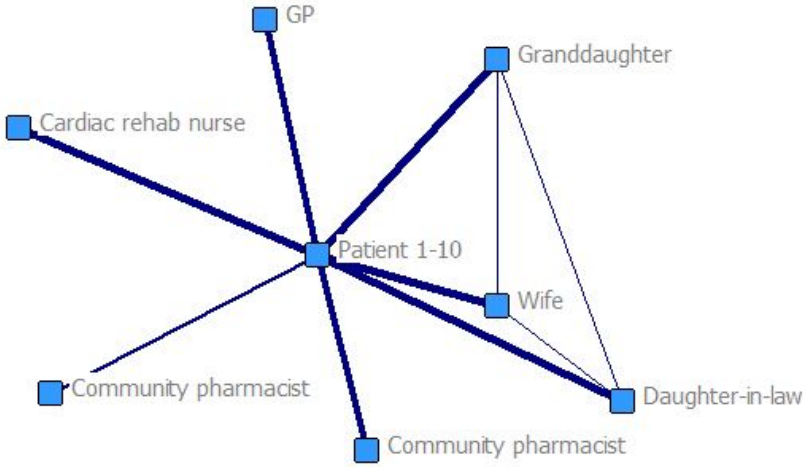


Figure 66: Sociogram of the ego-network of Patient 1.10

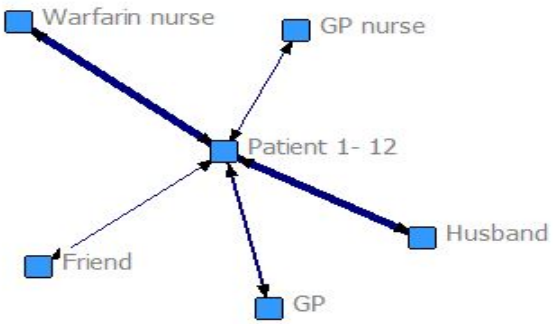


Figure 68: Sociogram of the ego-network of Patient 1.12

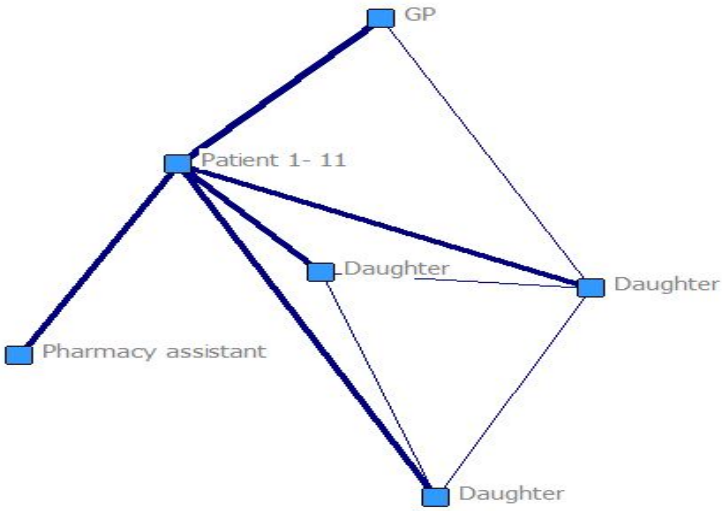


Figure 67: Sociogram of the ego-network of Patient 1.11

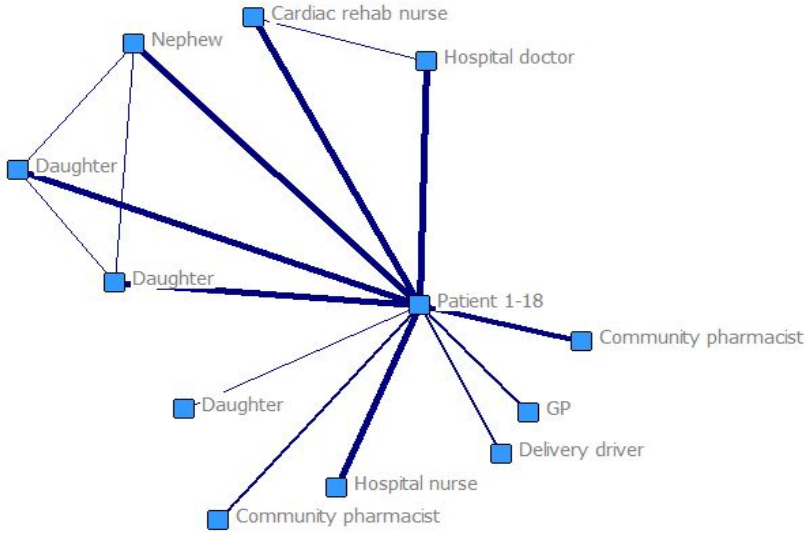


Figure 69: Sociogram of the ego-network of Patient 1.18

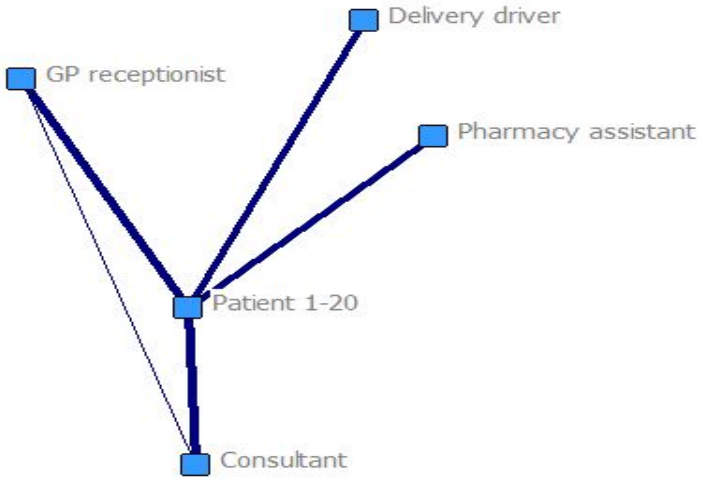


Figure 70: Sociogram of the ego-network of Patient 1.20

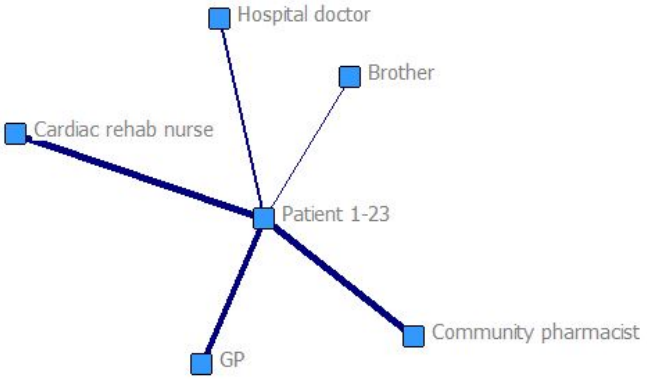


Figure 72: Sociogram of the ego-network of Patient 1.23

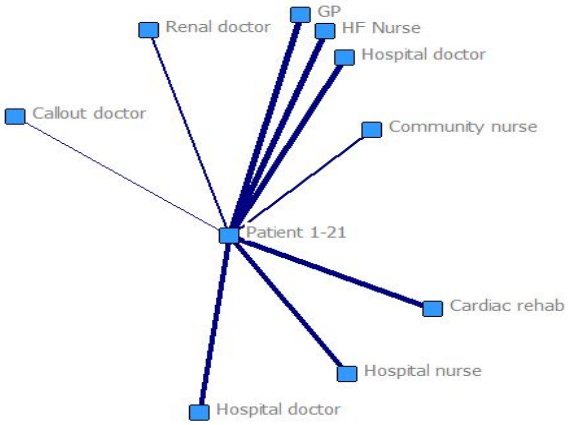


Figure 71: Sociogram of the ego-network of Patient 1.21

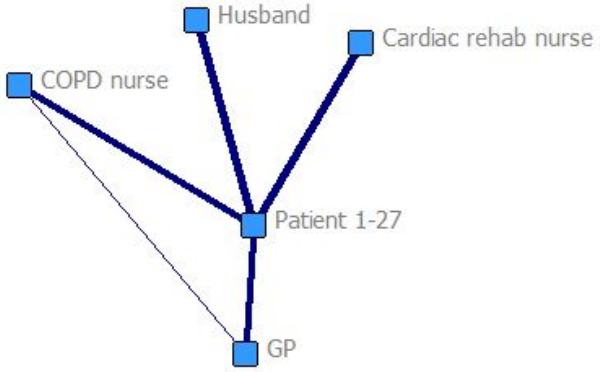


Figure 73: Sociogram of the ego-network of Patient 1.27

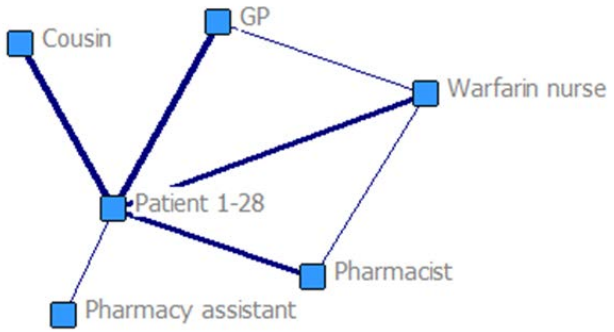


Figure 74: Sociogram of the ego-network of Patient 1.28

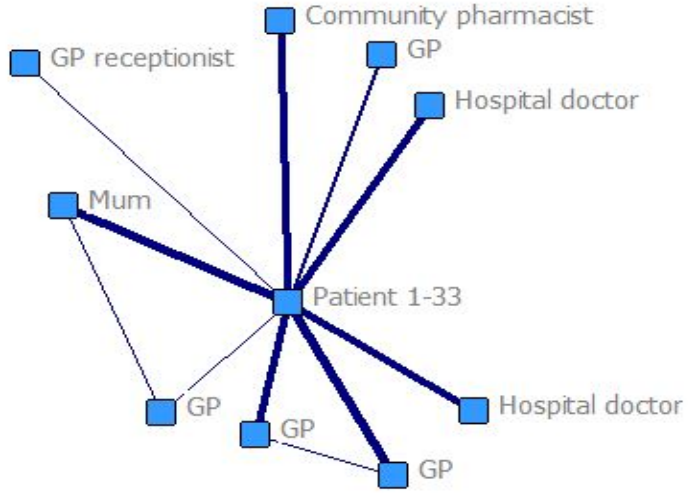


Figure 75: Sociogram of the ego-network of Patient 1.33

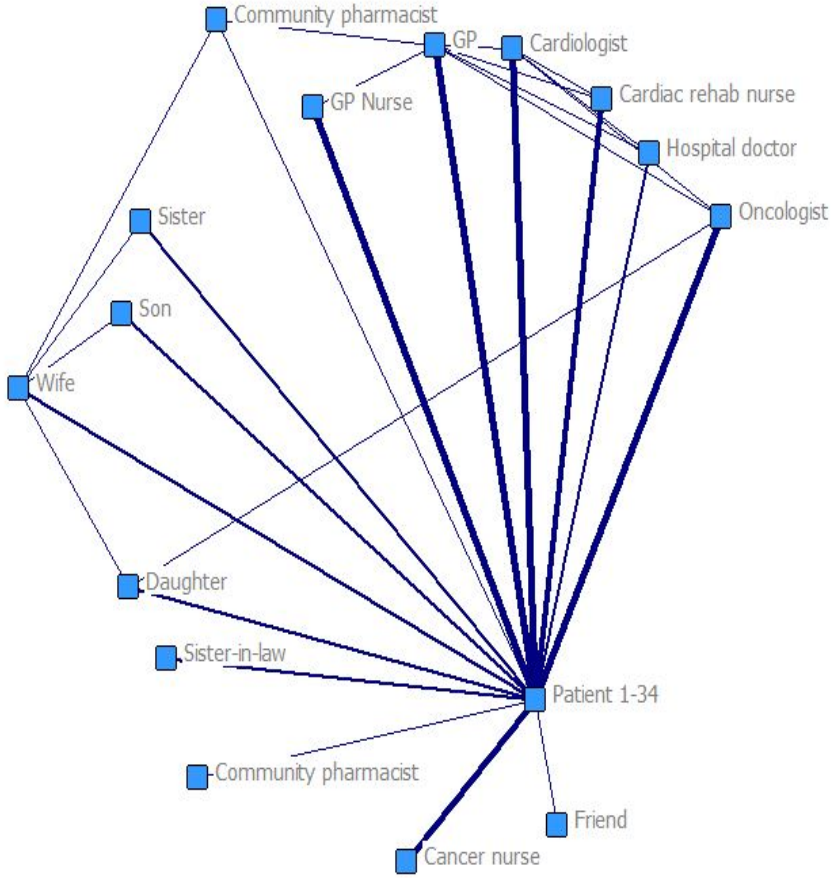


Figure 76: Sociogram of the ego-network of Patient 1.34

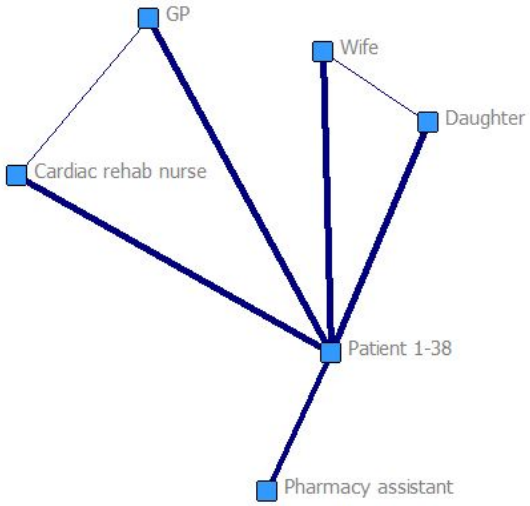


Figure 77: Sociogram of the ego-network of Patient 1.38

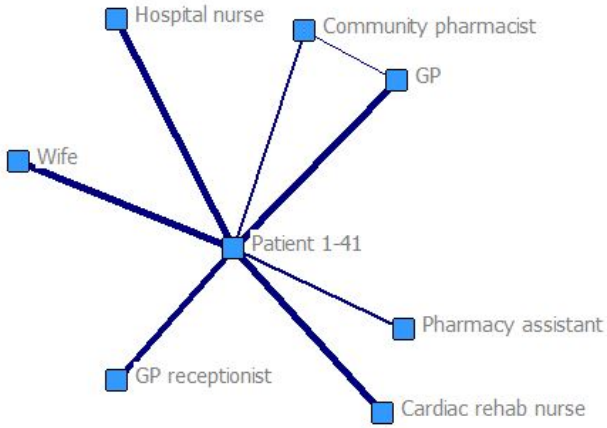


Figure 79: Sociogram of the ego-network of Patient 1.41

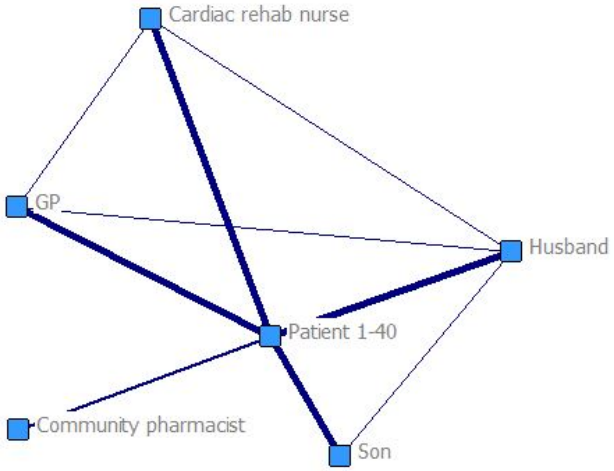


Figure 78: Sociogram of the ego-network of Patient 1.40

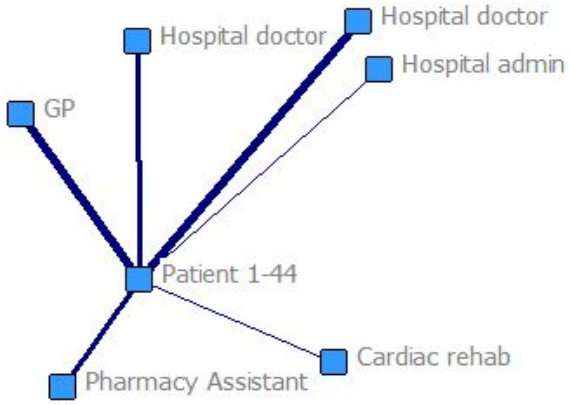


Figure 80: Sociogram of the ego-network of Patient 1.44

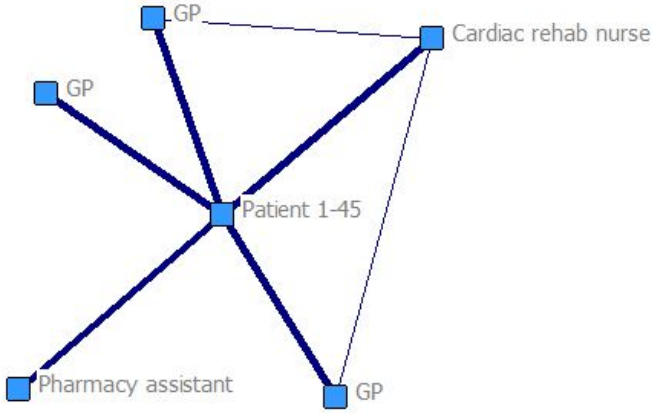


Figure 81: Sociogram of the ego-network of Patient 1.45

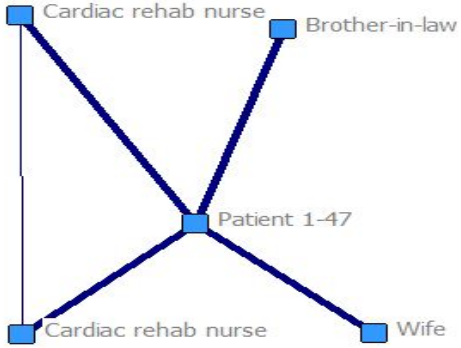


Figure 83: Sociogram of the ego-network of Patient 1.47

Figure 82: Sociogram of the ego-network of Patient 1.46

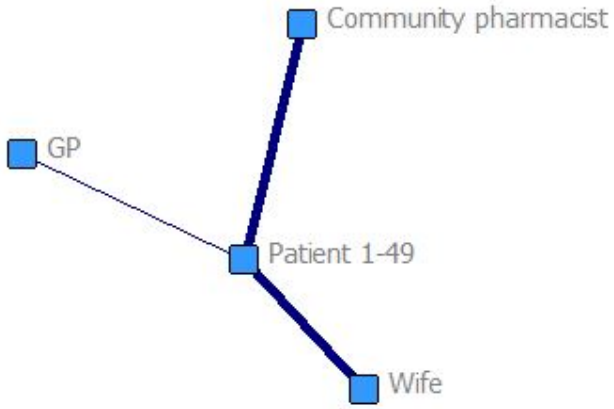


Figure 84: Sociogram of the ego-network of Patient 1.49

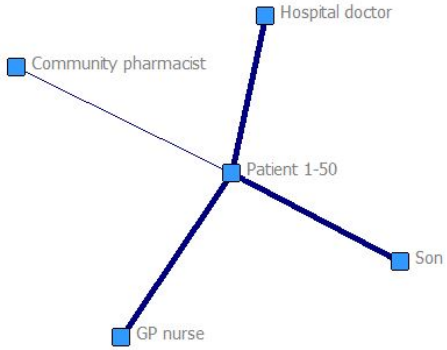


Figure 85: Sociogram of the ego-network of Patient 1.50

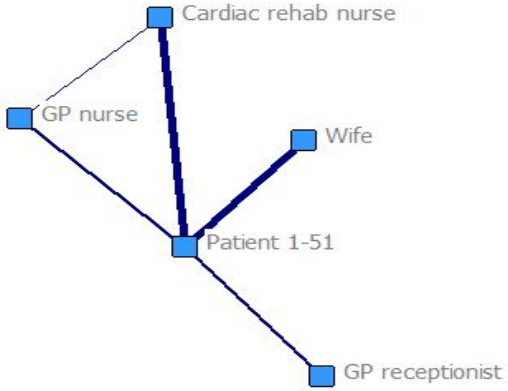


Figure 86: Sociogram of the ego-network of Patient 1.51

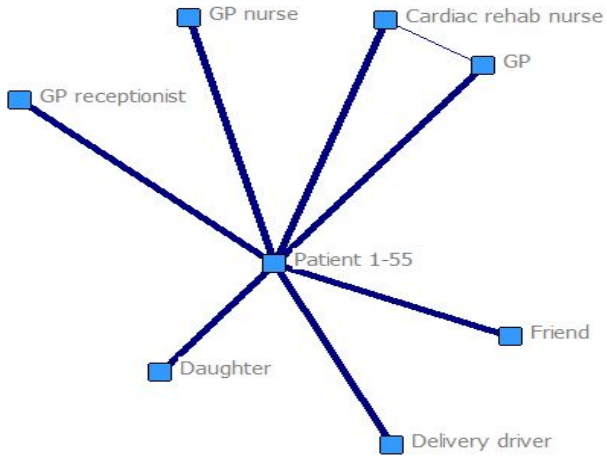


Figure 87: Sociogram of the ego-network of Patient 1.55

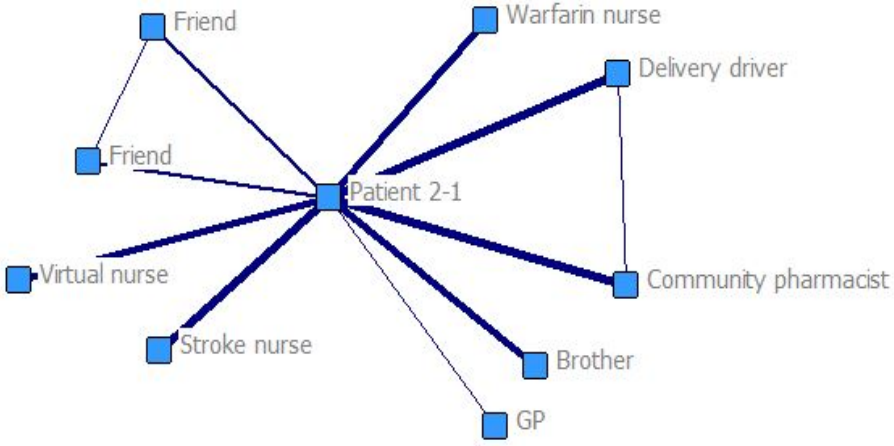


Figure 88: Sociogram of the ego-network of Patient 2.1

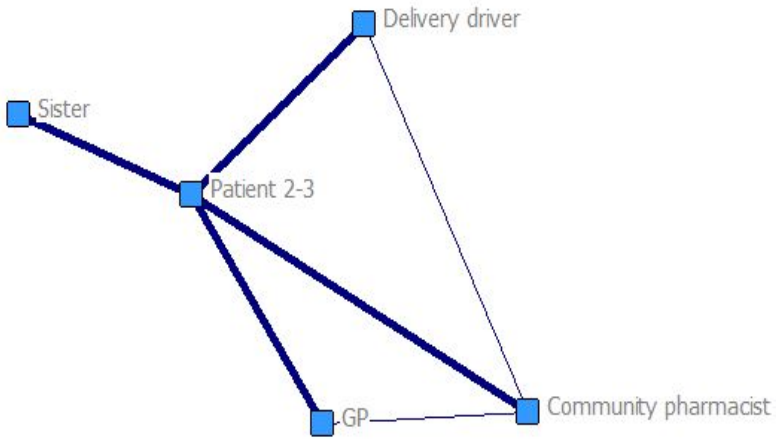


Figure 89: Sociogram of the ego-network of Patient 2.3

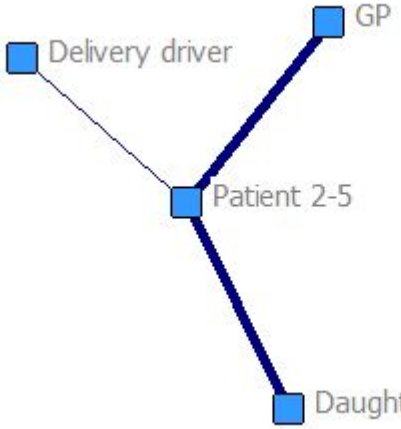


Figure 91: Sociogram of the ego-network of Patient 2.5

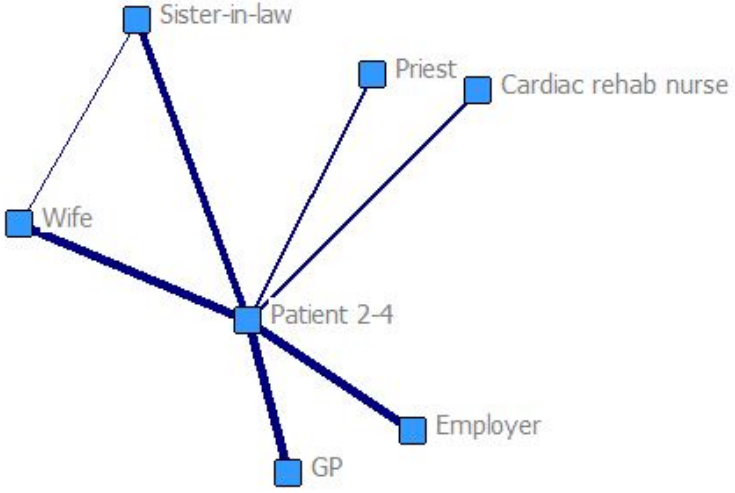


Figure 90: Sociogram of the ego-network of Patient 2.4

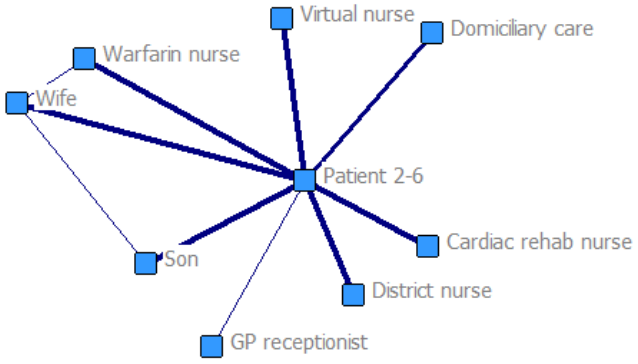


Figure 92: Sociogram of the ego-network of Patient 2.6

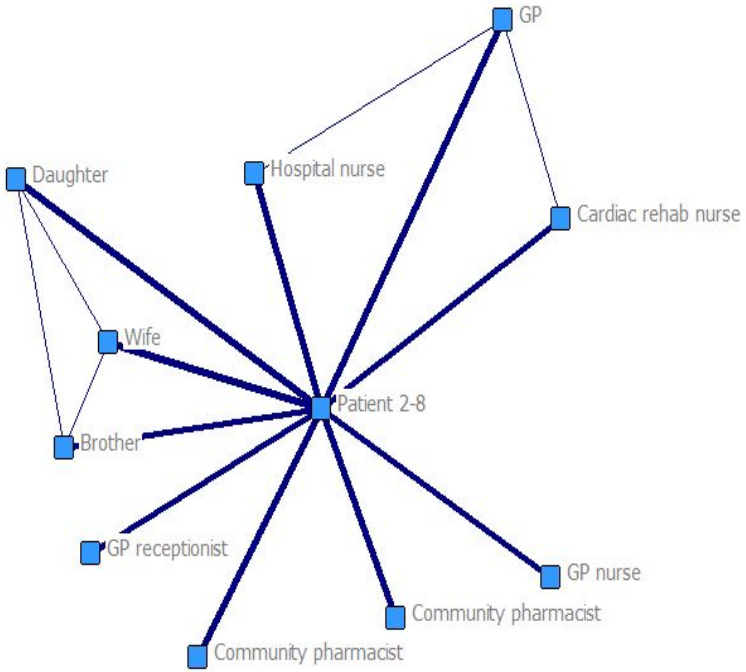


Figure 93: Sociogram of the ego-network of Patient 2.8

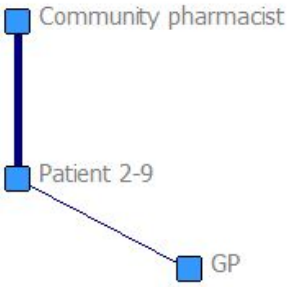


Figure 94: Sociogram of the ego-network of Patient 2.9

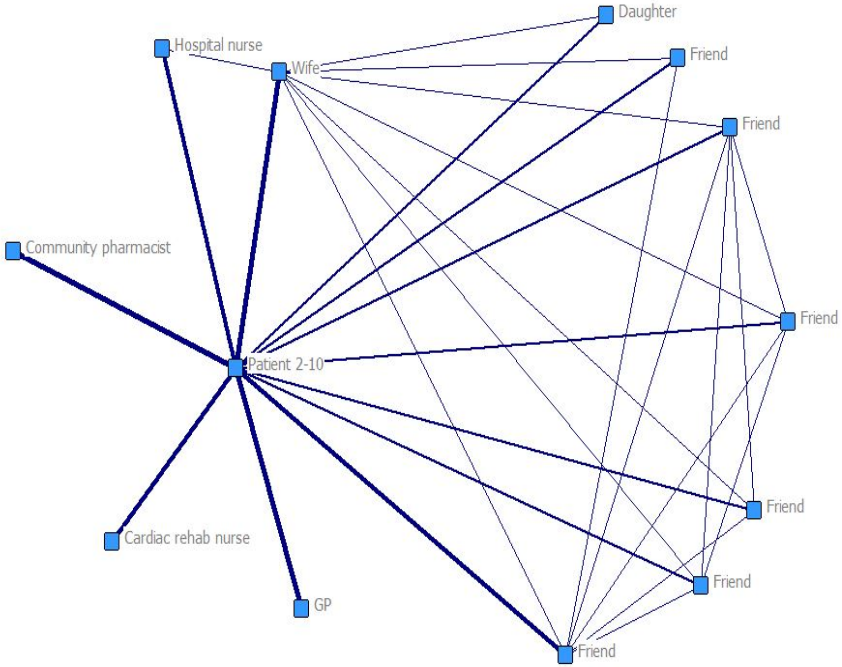


Figure 95: Sociogram of the ego-network of Patient 2.10

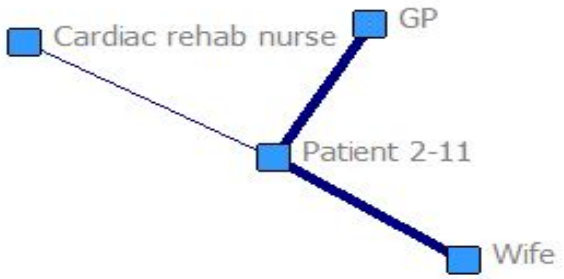


Figure 96: Sociogram of the ego-network of Patient 2.11

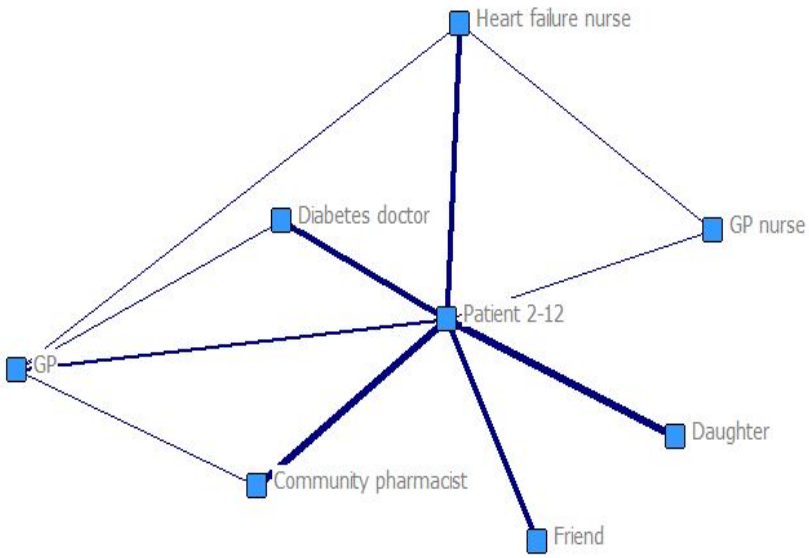


Figure 97: Sociogram of the ego-network of Patient 2.12

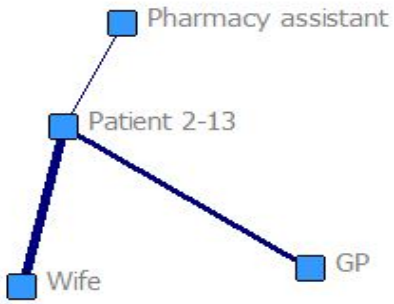


Figure 98: Sociogram of the ego-network of Patient 2.13

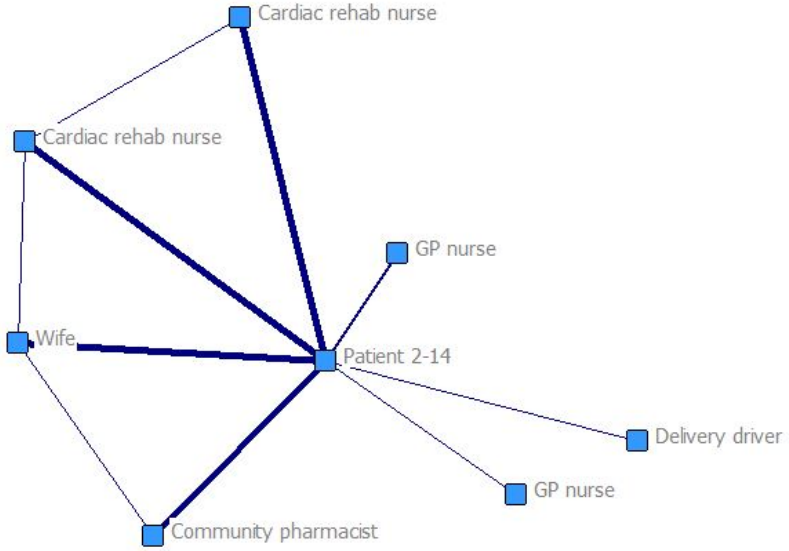


Figure 99: Sociogram of the ego-network of Patient 2.14

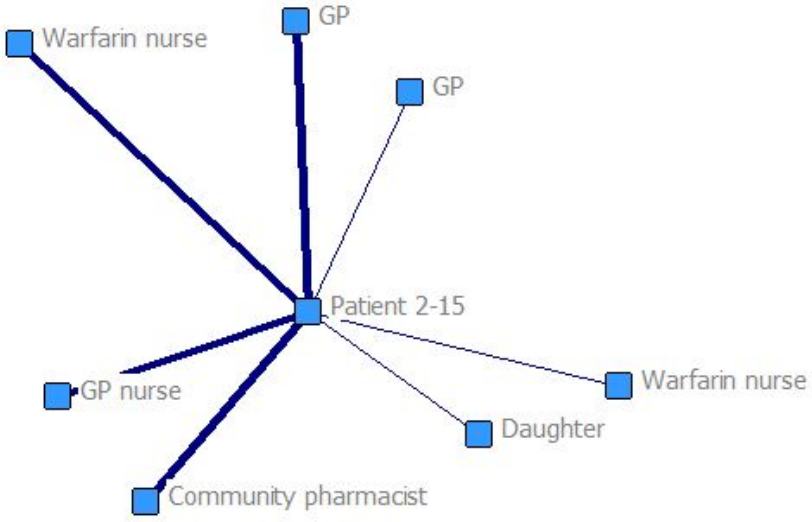


Figure 100: Sociogram of the ego-network of Patient 2.15

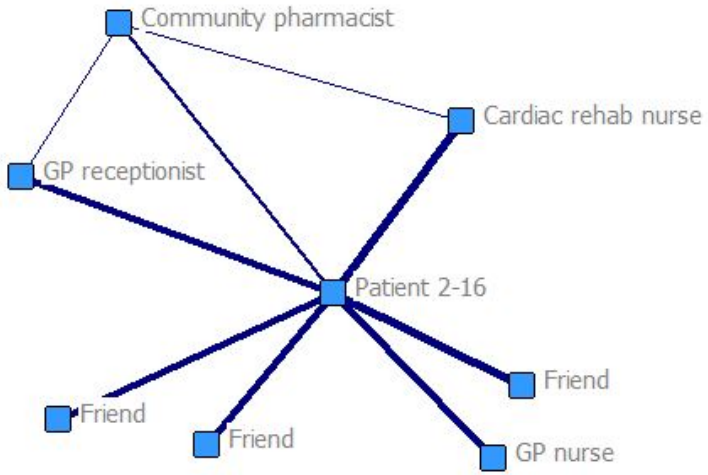


Figure 101: Sociogram of the ego-network of Patient 2.16

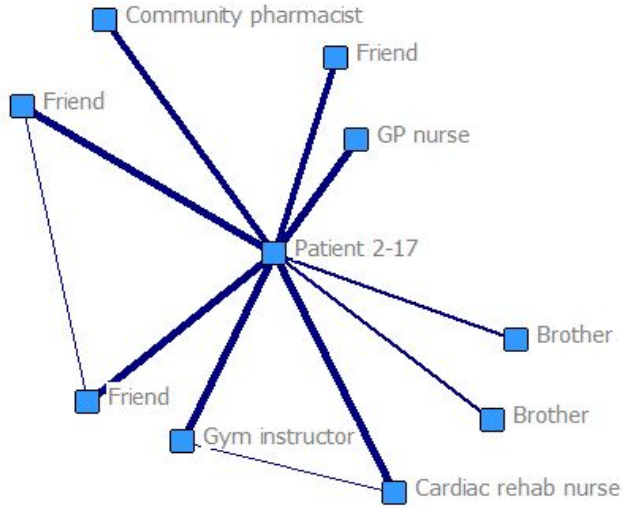


Figure 102: Sociogram of the ego-network of Patient 2.17

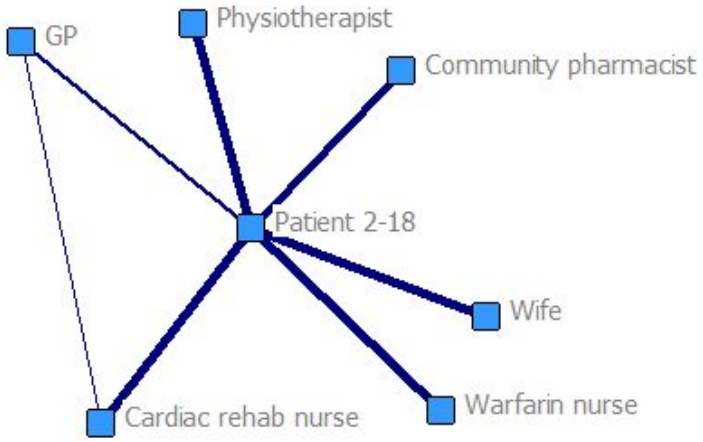


Figure 103: Sociogram of the ego-network of Patient 2.18

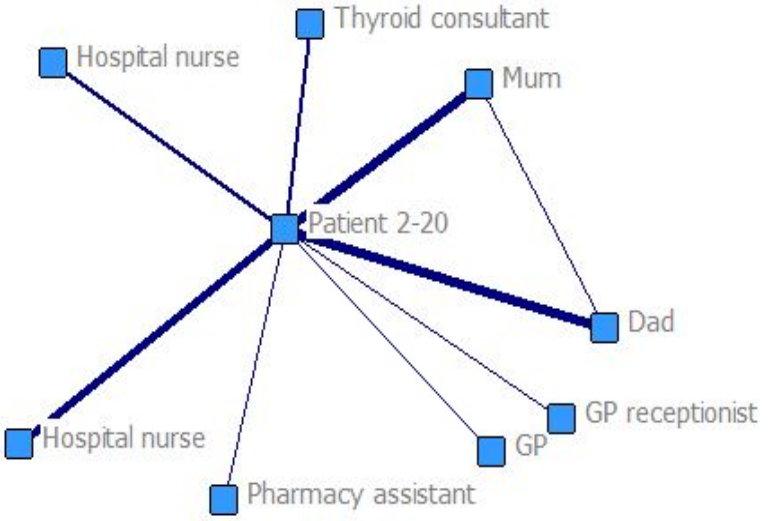


Figure 104: Sociogram of the ego-network of Patient 2.20

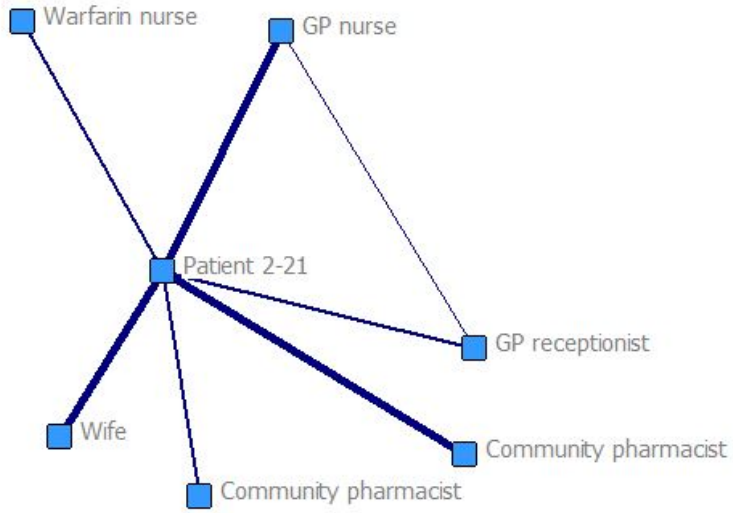


Figure 105: Sociogram of the ego-network of Patient 2.21

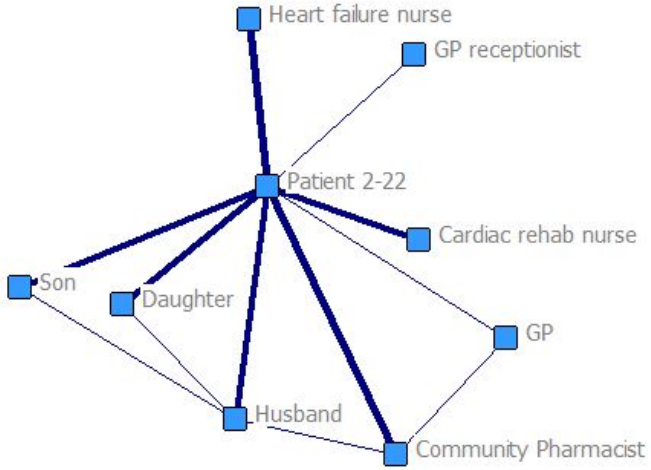


Figure 106: Sociogram of the ego-network of Patient 2.22

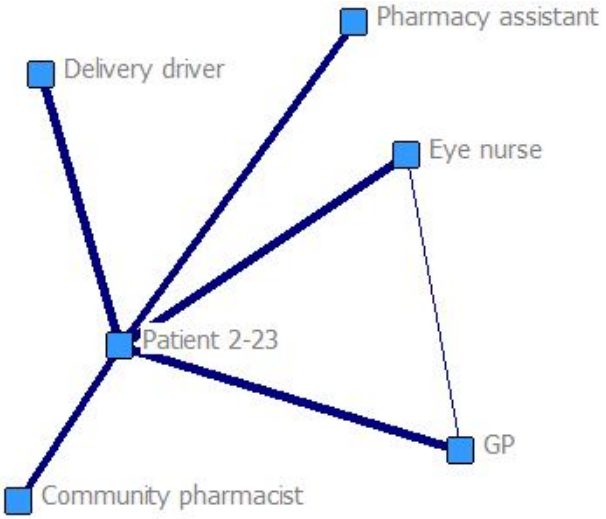


Figure 107: Sociogram of the ego-network of Patient 2.23

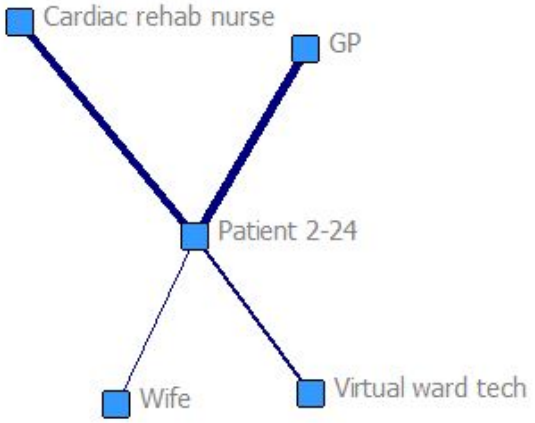


Figure 108: Sociogram of the ego-network of Patient 2.24

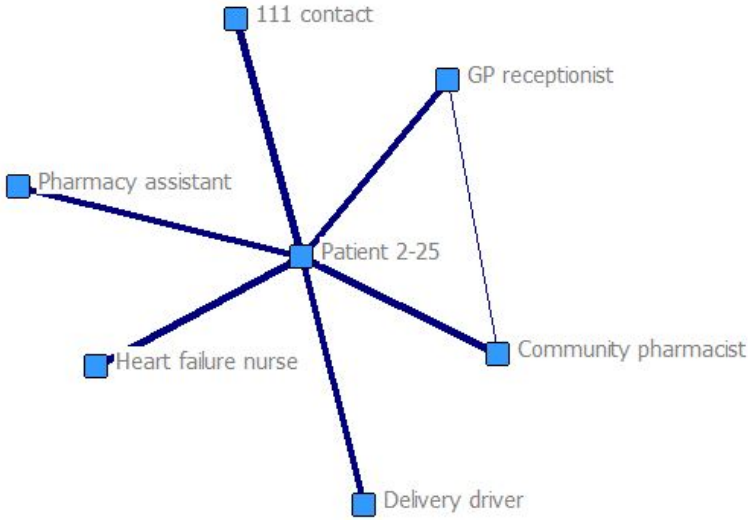


Figure 109: Sociogram of the ego-network of Patient 2.25

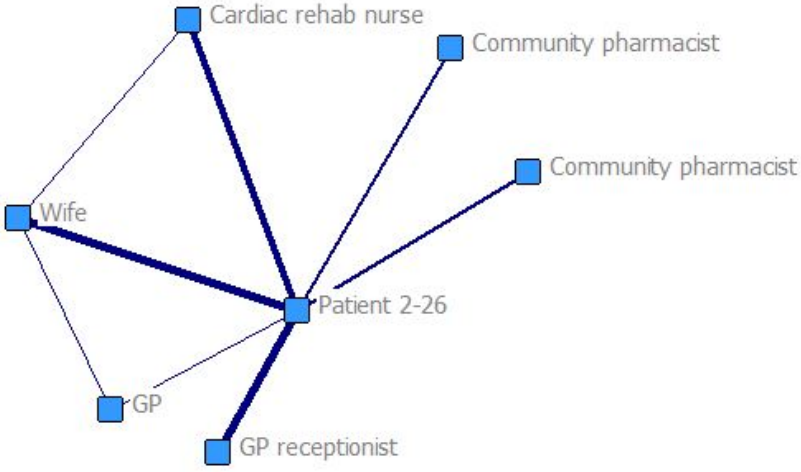


Figure 110: Sociogram of the ego-network of Patient 2.26

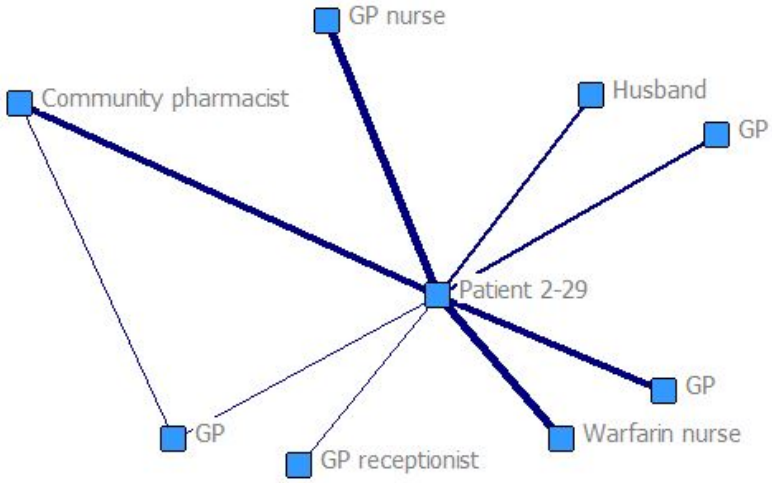


Figure 111: Sociogram of the ego-network of Patient 2.29

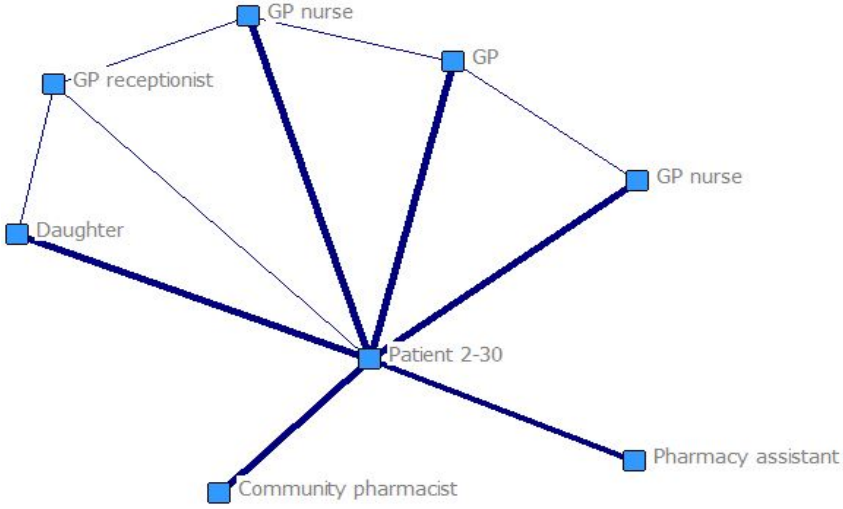


Figure 112: Sociogram of the ego-network of Patient 2.30

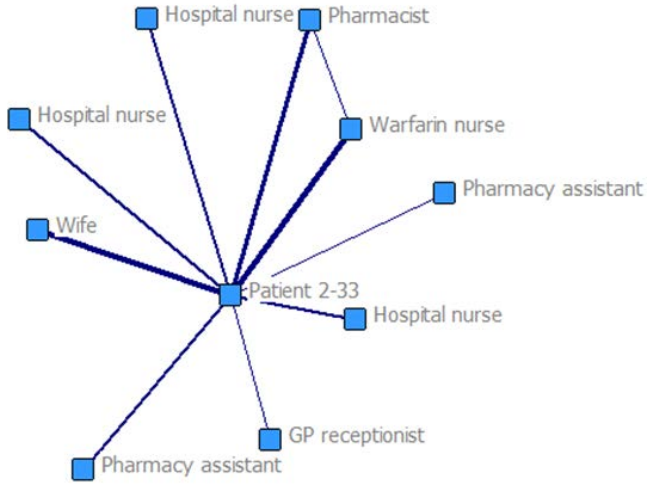


Figure 113: Sociogram of the ego-network of Patient 2.33

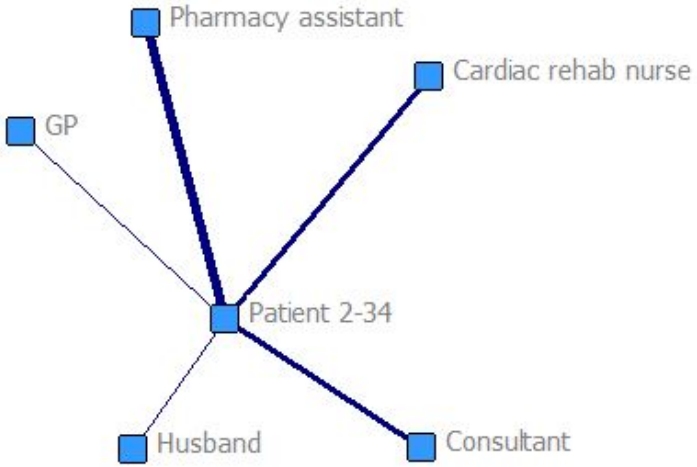


Figure 114: Sociogram of the ego-network of Patient 2.34

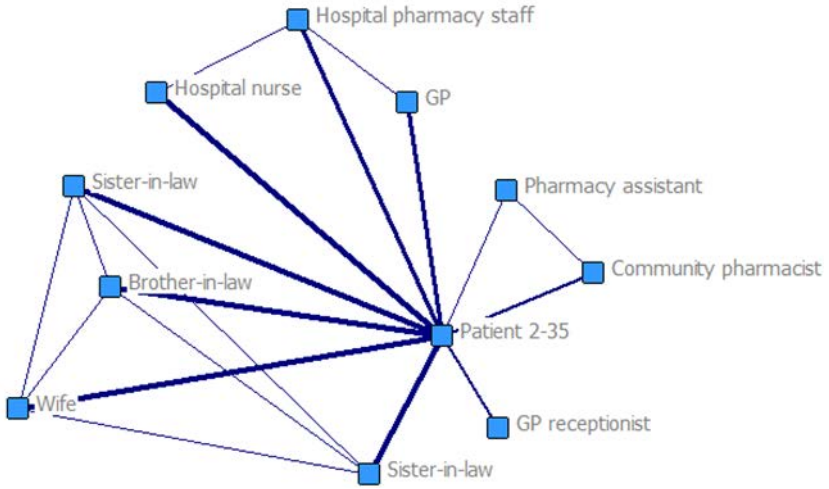


Figure 115: Sociogram of the ego-network of Patient 2.35

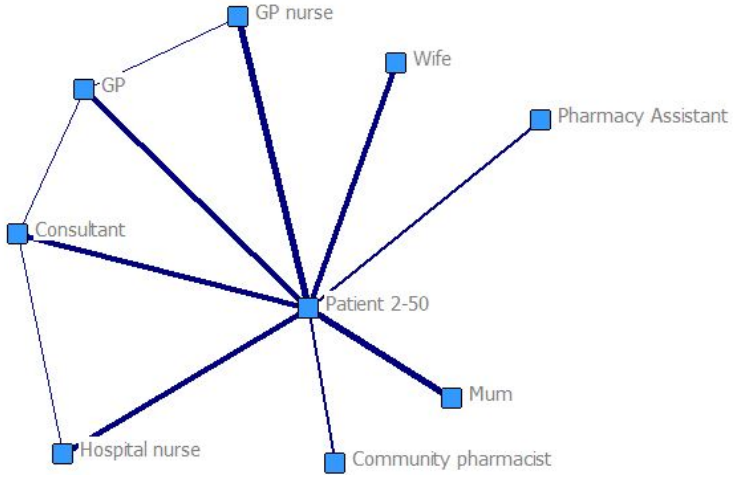


Figure 116: Sociogram of the ego-network of Patient 2.50

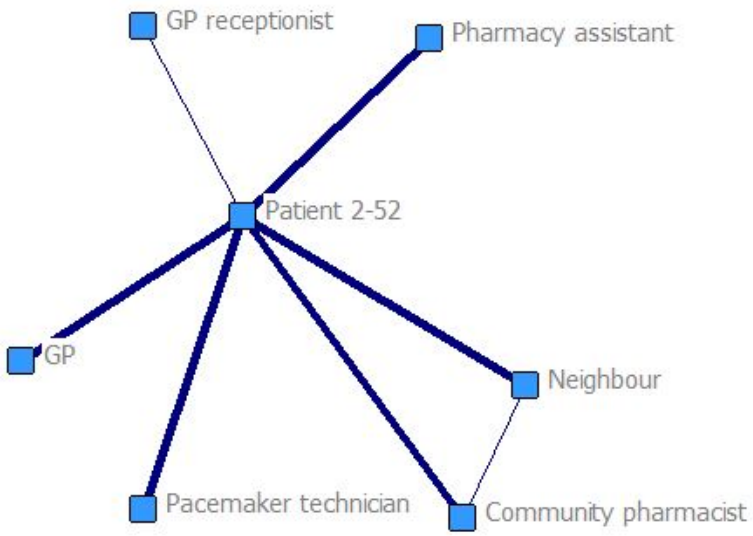


Figure 117: Sociogram of the ego-network of Patient 2.52

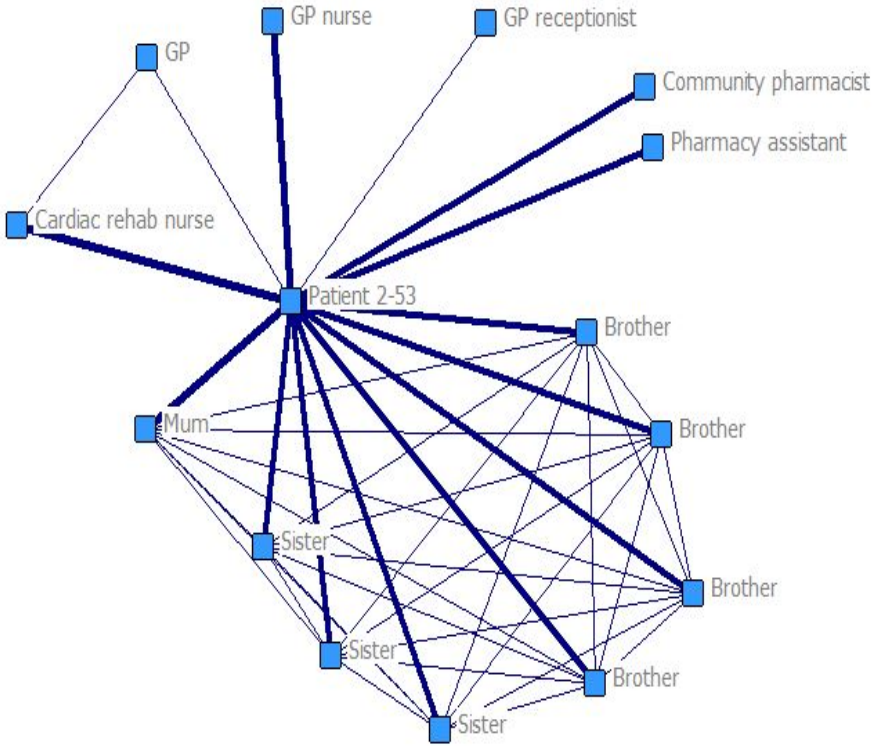


Figure 118: Sociogram of the ego-network of Patient 2.53

Appendix 4 – NHS REC approval letter

Business Services Organisation
Providing Support to Health and Social Care

Office for Research Ethics Committees Northern Ireland (ORECNI)

Customer Care & Performance Directorate
Office Suite 3
Lisburn Square House
Haslem's Lane
Lisburn
Co. Antrim BT28 1TW
Tel: + 44 (0) 28 9260 3107
Fax: + 44 (0) 28 9260 3619
www.orecni.hscni.net

HSC REC 3

12 August 2013

Ms Elizabeth Fylan Gwynn
Pre-doctoral researcher
University of Bradford
School of Pharmacy
Richmond Building, University of Bradford
Bradford
BD7 1DP

Dear Ms Fylan Gwynn

Study title: **Patients' medicines management safety networks: exploring the nature and frequency of patient medicines contacts. A social networks analysis.**
REC reference: **13/NI/0118**
IRAS project ID: **136510**

The Proportionate Review Sub-committee of the HSC REC 3 reviewed the above application on 08 August 2013.

We plan to publish your research summary wording for the above study on the NRES website, together with your contact details, unless you expressly withhold permission to do so. Publication will be no earlier than three months from the date of this favourable opinion letter. Should you wish to provide a substitute contact point, require further information, or wish to withhold permission to publish, please contact the Co-ordinator, Jan Daley. Email: jan.daley@hscni..net.

Ethical opinion

The study was well presented with no material ethical issues.

On behalf of the Committee, the sub-committee gave a favourable ethical opinion of the above research on the basis described in the application form, protocol and supporting documentation, subject to the conditions specified below.

Ethical review of research sites

The favourable opinion applies to all NHS sites taking part in the study, subject to management permission being obtained from the NHS/HSC R&D office prior to the start of the study (see "Conditions of the favourable opinion" below).

Conditions of the favourable opinion

The favourable opinion is subject to the following conditions being met prior to the start of the study.

Management permission or approval must be obtained from each host organisation prior to the start of the study at the site concerned.

Management permission ("R&D approval") should be sought from all NHS organisations involved in the study in accordance with NHS research governance arrangements.

Guidance on applying for NHS permission for research is available in the Integrated Research Application System or at http://www.rdforum.nhs.uk.

Where a NHS organisation's role in the study is limited to identifying and referring potential participants to research sites ("participant identification centre"), guidance should be sought from the R&D office on the information it requires to give permission for this activity.

For non-NHS sites, site management permission should be obtained in accordance with the procedures of the relevant host organisation.

Sponsors are not required to notify the Committee of approvals from host organisations.

It is the responsibility of the sponsor to ensure that all the conditions are complied with before the start of the study or its initiation at a particular site (as applicable).

You should notify the REC in writing once all conditions have been met (except for site approvals from host organisations) and provide copies of any revised documentation with updated version numbers. The REC will acknowledge receipt and provide a final list of the approved documentation for the study, which can be made available to host organisations to facilitate their permission for the study. Failure to provide the final versions to the REC may cause delay in obtaining permissions.

Approved documents

The documents reviewed and approved were:

Document	*Version*	*Date*
Covering Letter		30 July 2013
Evidence of insurance or indemnity	Bradford University professional and public indemnity cover and cover summaries	01 August 2012
Interview Schedules/Topic Guides	Patient Interview Schedule 1	16 July 2013
Investigator CV	Ms EF Gwynn; Prof G Armitage	
Other: Discharge Observation Contact Sheet	1	22 July 2013
Other: Medicines Contact Diary Sheet	1	16 July 2013
Participant Consent Form: Patient Consent Form	1	16 July 2011
Participant Consent Form: Staff Consent Form	1	16 July 2013
Participant Information Sheet: Patient Information Leaflet	1	16 July 2013
Participant Information Sheet: Staff Information Leaflet	1	16 July 2013

Protocol	1.0	16 July 2013
Questionnaire: Medicines Experience Survey	1	16 July 2013
REC application		26 July 2013
Summary/Synopsis	One-page summary 1	16 July 2013

Membership of the Proportionate Review Sub-Committee

The members of the Sub-Committee who took part in the review are listed on the attached sheet.

There were no declarations of interest.

Statement of compliance

The Committee is constituted in accordance with the Governance Arrangements for Research Ethics Committees and complies fully with the Standard Operating Procedures for Research Ethics Committees in the UK.

After ethical review

Reporting requirements

The attached document "After ethical review – guidance for researchers" gives detailed guidance on reporting requirements for studies with a favourable opinion, including:

- Notifying substantial amendments
- Adding new sites and investigators
- Notification of serious breaches of the protocol
- Progress and safety reports
- Notifying the end of the study

The NRES website also provides guidance on these topics, which is updated in the light of changes in reporting requirements or procedures.

Feedback

You are invited to give your view of the service that you have received from the National Research Ethics Service and the application procedure. If you wish to make your views known please use the feedback form available on the website.
information is available at National Research Ethics Service website > After Review

13/NI/0118 **Please quote this number on all correspondence**

We are pleased to welcome researchers and R & D staff at our NRES committee members' training days – see details at http://www.hra.nhs.uk/hra-training/

With the Committee's best wishes for the success of this project.

Yours sincerely

pp Angela Watson

Mr Stephen Brown
Chair of the Committee

Email: jan.daley@hscni.net

Enclosures: *List of names and professions of members who took part in the review*

"After ethical review – guidance for researchers" [SL-AR2]

Copy to: *Ms Jennifer Bellamy*
Research Support Unit
University of Bradford
Bradford
BD7 1DP

Ms Jane Dennison
Bradford Teaching Hospitals NHS Foundation Trust
Bradford Institute for Health Research
Bradford Infirmary
Duckworth Lane
Bradford
BD8 6JR

Appendix 5 – Chi square test results

This appendix presents the detail of the chi square tests performed on observation data. The tests are referred to in Section 4.3

A series of chi square tests explored the association between the type of medicine given to patients and the information they were given about them.

Medicines purpose

Achi-square test revealed a non-significant association between the category of medicine and whether they were told about the medicines purpose (X^2 (5)= 9.694, p=0.084). Staff told patients about their medicines purpose similar numbers of times regardless of the medicines type.

Medicines Dose

The chi-square test revealed a significant association between the category of medicine and whether staff told patients the dose of that medicine (X^2 (5)= 16.891, p<0.005). Exploration of the standardised residuals indicated that significantly more staff told patients about the dose of their beta-blocker than expected and fewer than expected told patients the dose of their GTN spray. Cramer's V indicated an effect size of 0.31 (values range between 0-1).

How to take medicines

The chi-square test with a Fisher's exact test correction revealed a significant association between the category of medicine and whether staff told patients how to take that medicine (X^2 (5)= 98.885, p<0.001). Exploration of the adjusted standardised residuals indicates that fewer people than expected were told how to take their beta-blocker, their statin, their Anti-platelet and their ACE inhibitor /ARB. Significantly more staff told patients how to use their GTN spray. Cramer's V indicated an effect size of 0.75.

Medicines frequency

The chi-square test revealed a non-significant association between the category of medicine and whether they were told about the medicines frequency (X^2 (5)= 0.717, p=0.984). Staff told patients how often they should take their medicines similar numbers of times regardless of the medicines type.

Medicines timing

The chi-square test revealed a significant association between the category of medicine and whether staff told patients when they should take them (X^2 (5)= 14.336, p<0.05*).* Staff told patients a when to use their GTN spray significantly more often than they did other medicines. Cramer's V indicated an effect size of 0.28.

Side effects
The chi-square test with a Fisher's exact test correction revealed a non-significant association between the category of medicine and whether patients were told about the side effects of that medicine (X^2 (5)= 3.073, p=0.677*).* Staff told patients about their medicines side effects similar numbers of times regardless of the medicine type.

Tests
The chi-square test with a Fisher's exact test correction revealed a non-significant association between the category of medicine and whether patients were told about tests they would need because of that medicine (X^2 (5)= 5.468, p=0.306). Staff told patients about tests similar numbers of times regardless of the medicines type.

Understanding checks
The chi-square test with a Fisher's exact test correction revealed a significant association between the category of medicine and whether staff checked that patients understood what they had been told about that medicine (X^2 (5)= 20.033*, p*<0.01*).* Exploration of the adjusted standardised residuals indicates that staff checked patients' understanding of what they were told about their GTN spray more frequently than for other medicines. Cramer's V indicated an effect size of 0.34.

Asking questions
The chi-square test with a Fisher's exact test correction revealed a non-significant association between the category of medicine and whether patients were told about tests they would need because of that medicine (X^2 (5)= 2.866, p=0.735). Patients asked questions about specific medicines similar numbers of times regardless of the medicines type.

What are patients told about their medicines at different sites?
Tables 3, 4 and 5 show the frequency (%) of the categories of information staff gave patients about their discharge medicines by site and by medicines category. A further series of chi-square tests explored the association between what patients were told about their medicines and the hospital site.

Medicines purpose
The chi-square test revealed a significant association between the discharge site and whether staff told patients the purpose of medicines whilst discharging them *(X^2* (2)= 42.185, p<0.001). Exploration of the adjusted standardised residuals indicates that staff on the ward in Site 1 and Site 2 told patients the purpose of their medicines significantly more frequently, whilst staff told people were the purpose of their medicines less frequently in the discharge lounge at Site 1. Cramer's V indicated an effect size of 0.49.

Medicines dose

The chi-square test revealed a non-significant association between the discharge site and whether staff told patients the dose of their medicines whilst discharging them (X^2 (2)= 1.159, p<0.57). Staff at each discharge site told patients about their medicines dose similar numbers of times.

How to take medicines

The chi-square test revealed a significant association between the discharge site and whether staff told patients how to take their medicines whilst discharging them (X^2 (2)= 8.317, p<0.05). Exploration of the adjusted standardised residuals indicates that staff on the ward in Site 1 told patients how to take medicines significantly more frequently. Staff in the Discharge Lounge at Site 1 told patients how to take their medicines significantly less frequently. Cramer's V indicated an effect size of 0.22).

Medicines frequency

The chi-square test revealed a non-significant association between the discharge site and whether staff told patients how often to take their medicines whilst discharging them (X^2 (2)= 4.049, p=0.133). Staff told patients about the frequency of their medicines a similar number of times at all sites.

Medicines timing

The chi-square test revealed a significant association between the discharge site and whether staff told patients when to take their medicines whilst discharging them (X^2 (2)= 7.870, p<0.05). Exploration of the adjusted standardised residuals indicated that staff on the ward and discharge lounge in Site 1 told patients how to take medicines significantly more frequently. Cramer's V indicated an effect size of 0.210.

Medicines side effects

The chi-square test with a Fisher's exact test correction revealed a significant association between the discharge site and whether staff told patients about side effects whilst discharging them (X^2 (2)= 21.003, p<0.001). Exploration of the adjusted standardised residuals indicated that staff on the ward in Site 1 told patients about side effects significantly more frequently. Staff in the discharge lounge in Site 1 told patients significantly less frequently. Cramer's V indicated an effect size of 0.344.

Tests

The chi-square test revealed a non-significant association between discharge site and whether staff told patients about required tests (X^2 (2)= 3.708, p=0.174). Staff told patients about required tests similar numbers of times regardless site.

Understanding checks

The chi-square test with a Fisher's exact test correction revealed a significant association between the discharge site and whether staff checked that patients understood what they had been told about medicines (X^2 (2)= 12.795, p<0.005). Exploration of the adjusted standardised residuals indicates that staff on the ward at Site 2 checked patients' understanding significantly more frequently and staff in the Discharge Lounge at Site 1 significantly less frequently. Cramer's V indicated an effect size of 0.27.

Asking questions

The chi-square test with a Fisher's exact test correction revealed a non-significant association between site and whether patients asked questions about their medicines (X^2 (2)= 4.171, p=0.128). Patients asked questions about specific medicines similar numbers of times regardless of the site.

Additional information

Using a Fisher's Exact test correction, a significant association was indicated between the discharge site and whether patients were told how to get repeat medicines (X2(2)=6.337, p<0.05). Cramer's V indicated an effect size of 0.37. Exploration of the adjusted standardised residuals indicated that staff at Site 2 gave this information significantly more frequently.

A non-significant association was indicated between the discharge site and whether staff highlighted written take home medicines information to patients (X^2(2)=5.139, p=0.081). Staff gave this information a similar number of times regardless of the site.

A significant association was indicated between the discharge site and whether staff explained how the hospital would communicate with the patient's primary care teams (X^2(2)=10.130, p<0.01). Cramer's V indicated an effect size of 0.43. Staff give this information significantly more frequently on the ward in Site 2 and significantly less frequently in the discharge lounge at Site 1.

Appendix 6 – Assessment of the safety incidents reported by patients

ID	**1.1**
Patient age	72
Safety incident description	Uses a knife to get into medicines packaging because he finds the metal push out packs difficult to get into. Two sets of Warfarin tablets were missing from his repeat medicines. "Well, it's supposed to have been done by computer from the surgery to the thing and they've been put in…oh, they forgot…two lots were missing, not this last time, the time before where it was supposed to have gone computerised and they'd put Warfarin tablets in, just one packet of pink ones, I think that's 5mg and I don't take them 'cause it can vary from every…like, at the moment I'm on thee and a half, one blue and one white, whereas just over two month ago I was on one blue, one brown, one white."
Assessor 1	Yes
Assessor 2	Yes

ID	**1.8**
Patient age	79
Patient gender	
Safety incident description	Information about increased dose of Bisoprolol not on GP system after a week. Patient was unable to get a repeat prescription for this higher dose when he needed to. The GP phoned him the next day and said that the paperwork had just arrived. Patient: "I suspect it had been there, but they were playing catch up with the paperwork to actually enter it onto the system."
Assessor 1	Yes
Assessor 2	Yes

ID	**2.35**
Patient gender	59
Safety incident description	One week after discharge his right foot swelled up from gout. *He has been taking* Allopurinol daily and hasn't had a gout attack for years. He decided to take Coltrazine. He told his GP he had done this and the GP 'went into a flat panic'. The patient explained there may be an interaction with his statin (simvastatin). The patient recalled being told in hospital he could take Coltrazine so he rang the ward and was put through to the hospital pharmacy. The pharmacy then rang the GP and explained why he could use the Coltrazine. The patient explained 'it all got sorted out, but that was panic stations at one point'.
Assessor 1	No
Assessor 2	No

ID	**2.10**
Patient gender	66
Safety incident description	This patient was mistakenly prescribed a statin in the hospital to which he is allergic. The hospital later apologised to him. Patient was getting what he thought was severe chest pains which he thought may be due to his Ramipril dose. The patient nearly stopped taking Rampril because he thought the chest pains were a side effect. He saw his GP, who advised him to continue with his hospital medicines as prescribed. The hospital sister later suggested he should have been on a PPI because he had been taking aspirin for so long and this may be causing his pain. He saw his GP the following day who agreed that he should have been prescribed a PPI earlier.
Assessor 1	Yes
Assessor 2	2 incidents, allergy to statin = Yes Aspirin and PPI, would depend whether the patient was a known risk for GI bleed. I don't think that it is routine to prescribe a PPI with low dose aspirin unless the patient is a known risk. If he were a risk and the hospital and the GP didn't pick up on this risk, then YES.

ID	**1.41**
Patient age	65
Safety incident description	Went for repeat prescription to the GP and the information about his new medicines from the hospital was not on the GP system. The receptionist at his GP surgery photocopied the discharge summary, but only the first page of it so he only got some of his repeat medicines. In the process of rectifying this, the GP surgery issued two prescriptions and he received two sets of medicines simultaneously.
Assessor 1	Yes
Assessor 2	Yes

ID	**1.44**
Patient age	52
Site	BRI
Safety incident description	Patient was sent the wrong information by the hospital before a stress test. She was told to stop taking Bisoprolol before the test in a letter but the consultant had wanted her to take the test whilst taking a betablocker. She stopped taking her betablocker as instructed. This was attributed to a clerical error.
Assessor 1	Yes
Assessment DN	Yes

ID	**1.47**
Patient age	72
Safety incident description	The GP practice didn't have this patient's medicines list when he tried to order his repeat medicines.
Assessor 1	Yes
Assessor 2	Yes

ID	1.49
Patient age	79
Safety incident description	The repeat medicines supplied by the GP team had different brand names and very different packaging to his discharge medicines. As a result, the patient believed the GP had prescribed even more medicines in addition to those given to him in hospital and he proceeded to take double the dose of at least three cardiology medicines used to treat high blood pressure and angina. He described becoming disorientated, nauseous and believes he lost consciousness for about ten minutes. His wife insisted he contact the local pharmacist, who asked him to come into the pharmacy. The pharmacist subsequently banded the medicines boxes together to help him understand which brands were the same medicines.
Assessor 1	Yes
Assessor 2	Yes

ID	2.15
Patient age	75
Safety incident description	This patient is unable to read and suffers from memory loss due to a stroke. He was unable to read the instructions on his blister pack properly and he mixed up his doses in the blister pack, taking the wrong doses at the wrong times and double dosing. He also described mixing up his warfarin doses.
Assessor 1	Yes
Assessor 2	Yes

ID	2.22
Patient age	62
Safety incident description	The patient was supplied a repeat set of medicines without the new post-hospital medicines. She rang the surgery and they told her they couldn't find the note from the hospital. Her pharmacist then phoned the surgery, which had found the discharge summary, and issued an emergency supply. The next day but a different pharmacy (which was not the pharmacy she had dealt with) delivered her another repeat set.
Assessor 1	Yes
Assessor 2	Yes

ID	1.29
Patient age	66
Safety incident description	This patient had an MUR and the pharmacist told her she shouldn't be on omeprozole with clopidogrel and said she would contact the patient's GP to see if they could be changed. The patient didn't hear anything from the pharmacy or the GP but put her repeat prescription in ordering omeprozole but when she received the medicines they'd written lansoprazole for the following repeat, but given her omeprozole. She was left confused by the process.
Assessor 1	Yes - written prescription and medicines did not match which impacted on the patient
Assessor 2	No (think this was very badly handled, interaction is documented but not dangerous, antiplatelet effect is reduced. Risk would depend on indication for omeprazole/lansoprazole. Risk of GI bleed if stopped

	taking.

ID	**2.25**
Patient age	80
Safety incident description	Patient was supplied the incorrect form of aspirin by her GP – she is unwell if she takes uncoated aspirin (described feeling sick and dizzy): “So there's enough wrong me, without being sick on top”. She suspects the surgery may not have read the hospital notes.
Assessor 1	Yes
Assessor 2	Yes

ID	2.30
Patient age	62
Safety incident description	Patient began to feel unwell when her dose of betablocker was increased following her pacemaker check, which revealed she had experienced palpitations. Managed to She had trouble speaking to a GP about it – her daughter had to intervene and speak to the receptionist – but subsequently she spoke to a GP on the telephone who reduced the dose to its previous level.
Assessor 1	No
Assessor 2	No

ID	**2.52**
Patient age	67
Safety incident description	His new medicines including a betablocker were not supplied with his repeat medicines. He noticed when he checked the medicines he received in the pharmacy. The pharmacy offered to contact the GP surgery for him. He halved his dose of Bisoprolol without consulting an HCP because he was feeling flutter. During a pacemaker check he told the technician what he’d done and they advised him to resume his normal dose. The flutters were eventually attributed to a faulty pacemaker connection
Assessor 1	Yes (two PSIs here – drug omission and faulty connection?)
Assessor 2	Yes (for failure to supply beta blocker)

ID	**1.27**
Patient age	52
Safety incident description	Hospital gave her soluble Aspirin and her doctor gave her ‘crunchy’ Aspirin. Her husband checked with the pharmacist who reassured him that it was alright to have the different type of aspirin.
Assessor 1	No
Assessor 2	No

ID	**1.34**
Patient age	70
Safety incident description	Couldn’t order some of his repeat medicines using the online system as some are marked for review. He needed to see his GP.
Assessor 1	No
Assessor 2	No

ID	**2.33**
Patient age	65
Safety incident description	The patient described being prescribed 50mgs of flecainide twice a day by the hospital. The GP then prescribed 100mg tablets the patient didn't notice the change and continued taking one pill twice a day which meant he was having twice the dose for about three weeks.
Assessor 1	Yes
Assessor 2	Yes

ID	**1.46**
Patient age	50
Safety incident description	The patient described suffering from bad skin irritation. The GP stopped his clopidogrel and the itching became less severe.
Assessor 1	No
Assessor 2	No

ID	**2.24**
Patient age	64
Safety incident description	Patient has stopped taking all his cardiology medicines because he doesn't think they are working for him. "What's the point taking something which it doesn't relieve any symptoms?"
Assessor 1	No
Assessor 2	No (for action/inaction of HCP, but Yes for risk to patient)

ID	**2.26**
Patient age	71
Safety incident description	The patient was given a GTN spray which he was confident about using. The first repeat prescription issued by his GP after leaving hospital replaced the spray with GTN tablets. He had less confidence in the GTN tablets and when he raised concerns with the GP practice the receptionist relayed a message that the practice did not issue sprays, only pills: "I weren't actually happy because I've been given all this information on spray and written information but just on spray not anything else, just on this spray and then to get another and you can't have one, you've to have pills with no information." A GTN spray was later issued.
Assessor 1	Yes (communication failure)
Assessor 2	Yes

ID	**2.17**
Patient age	67
Safety incident description	Pharmacy supplied simvastatin instead of atorvastatin after the patient mentioned that she wanted smaller tablets to swallow – the pharmacy had consulted her GP. She was worried that she should be taking atorvastatin because the hospital doctor told her he wanted her to be on atorvastatin. Her cardiac rehab nurse also told her she should really be on Atorvastatin. She is now confused about the dose she should be taking – her Atorvastatin was 80mg and the simvastatin is 40mg. She asked the pharmacy if she should take two of the Simvastatin but was told to just take one, which doesn't make sense to her.
Assessor 1	No

Assessor 2	No (assuming decision of GP is correct, although this could be a Yes if the relative potencies of simvastatin 40mg compared with atorvastatin 80mg are taken into account and patient has very high cholesterol)

ID	**2.14**
Patient age	67
Safety incident description	Patient continued having bad angina attacks after leaving hospital. He had spoken to the cardiac rehab nurse twice, and the pharmacist on the telephone before the cardiac rehab sister identified four weeks after discharge that he should have been prescribed isosorbide mononitrate as one of his TTOs. “She asked me was I not taking this certain tablet, I said no, and she told me I should have been on it when I left hospital, and since I’ve subsequently started taking that tablet everything’s started to settle down.”
Assessor 1	Yes
Assessor 2	Yes

ID	**1.18**
Patient age	58
Safety incident description	Patient gets confused by the staged supply of her medicines by the pharmacist: “As I told you I was eating only thyroid medicine, so this is 150mg, they give me 150mg on separate… so first 100mg and then after a few days the 50mg. So I'm really confused with these, you know, with this situation.
Assessor 1	Unclear – if the patient is on 150mgs and the staged supply means she will sometimes only have 100mgs tablets (and I would have thought that splitting tabs should ideally be carried out by a pharmacist) – while waiting for the 50mgs tablets, this could be construed as a PSI as she cannot receive the correct dose on a continuing basis
Assessor 2	No, but this is not good service

ID	**1.33**
Patient age	39
Safety incident description	Patient became ill after leaving hospital got a sore mouth and thrush and the GP said it was a side effect of one of her medicines (an antibiotic) and once she stopped taking them she’d feel fine. She became very confused and lost the feeling on one side of her face. Her friend contacted the GP and it took three hours for them to ring back and they requested she visit the surgery and suggested that she get a taxi when she said she was too unwell to attend. The GP then suggested she was anxious and told her again to come to the surgery and ended the call. He phoned back five minutes later and suggested she wasn’t getting enough oxygen to your brain. Three hours later a different doctor visited her at home.
Assessor 1	Not enough clarity to decide – I would exclude
Assessor 2	I would think initial GP reaction was correct but that there was no connection between the thrush and loss of sensation to the face and this should be investigated, which it was, problematic communication rather than safety risk

ID	2.6
Patient age	70
Safety incident description	The patient explained that he has been receiving different brand medicines from the pharmacy. “Well I was taking what the doctor had said, that’s all you can do, I know the boxes keep changing… The chemist keeps changing them and you’re not getting the same.”
Assessor 1	No
Assessor 2	No

ID	2.8
Patient age	75
Safety incident description	Patient explained that isosorbide mononitrate was making him dizzy. A nurse on the phone suggested he take it with orange juice and this has helped alleviate the side effect
Assessor 1	No
Assessor 2	No

ID	2.20
Patient age	62
Patient gender	Female
Site	RBH
Safety incident description	Patient is sometimes dizzy, has achy legs black spots in front of her eyes. She suspects that side effects may be due to her medication.
Assessor 1	No (but minimal knowledge on the case)
Assessor 2	No

ID	2.53
Patient age	50
Safety incident description	Patient was getting mixed up with her medicines because there were so many of them and reported that sometimes she would double dose. She now has a blister pack. Her repeat prescription after discharge included aspirin when she reported the hospital had written to the GP to instruct them not to prescribe aspirin.
Assessor 1	Yes (part 2 only)
Assessor 2	Yes

ID	2.9
Patient age	73
Safety incident description	Patient reported only taking half his dose of Zicron as he thought it was making him feel nauseous. He has not discussed this with a HCP.
Assessor 1	No
Assessor 2	No

ID	2.11
Patient age	68
Safety incident description	Nicorandil was missing from the repeat prescription when his wife put in the repeat request. This was about 1 week after he left hospital and his wife handed in the repeat slip issued with his previous medicines The patient decided to stop taking nicorandil soon after leaving hospital because of the severe headaches he was experiencing. He was his GP soon after to discuss this.
Assessor 1	Yes (part 1 only)
Assessor 2	Yes

ID	1.55
Patient age	61
Safety incident description	Patient reported feeling breathless and wondered if it was caused by her medicines. She was too scared to stop taking them.
Assessor 1	No
Assessor 2	No, (assuming not known asthmatic who could have been prescribed a beta blocker).

Appendix 7 – Conference abstracts

The following pages contain the published abstracts from conference presentations of the work in this thesis. All abstracts are reproduced with kind permission.

observations of doctors' ward rounds, pharmacists' ward visits and nurses' drug administration rounds, to determine if and how healthcare professionals facilitate patient involvement in medication safety. The study had a patient and clinical engagement group whose lay representatives suggested that lay people should be involved in these observations in parallel with our researchers, a suggestion we adopted. The aim of the work presented here was to describe the benefits and challenges of having lay people conduct these observations, in order to inform the future role of lay people conducting this type of research.

Observations took place between January and June 2014. NHS ethics approval was obtained for the main study but not required to conduct these additional interviews as lay observers were not recruited via the NHS.

We conducted semi-structured interviews with the 3 lay members involved in data collection and the 4 research team members involved in their recruitment, training or support on the wards. The topic guide explored lay observers' and researchers' views of the benefits and challenges of lay involvement in the observations; it was informed by preliminary discussions with our lay observers and researchers. The interviews were transcribed verbatim and coded openly, using NVivo 8 for assistance. A second researcher independently coded 30% of interviews.

In addition, secondary qualitative analysis of the observational data was carried out to identify the specific input of lay observers into the study findings.

The lay members and researchers reported that lay members added value to the data by bringing new perspectives. Some challenges were identified including the infrastructure not being in place to support this specialist lay research role, differing paradigms of research governance held by the public and healthcare professionals, and difficulties in recruitment of a diverse range of lay observers.

The secondary analysis demonstrated that five codes were added to the framework as a result of the lay observations.

In this study, including observations by lay members added value to the findings. There is a need to build infrastructure in NHS trusts to support this involvement.

This study was limited to interviews with the small number of lay observers and researchers who were involved in one research project. It is therefore unclear whether theoretical saturation was reached or how generalisable the findings are. However the full relevant population was interviewed and, given the scarcity of studies addressing this issue, these findings can help inform future lay involvement in data collection.

1. Snape D, Britten N, Froggat K, Gradingre F, Lobban F, Popay J, Wyatt K, Jacoby A. Exploring perceived barriers, drivers, impacts and the need for evaluation of public involvement in health and social care research. A modified Delphi study. *BMJ Open* 2014; 4: e004943. doi:10.1136/bmjopen-2014-004943.
2. Domecq JP, Prutsky G, Elariyah T, Wang Z, Nabhan M, Shippee N, Brito JP, Boehmer K, Hasan R, Firwana B, Erwin P, Eton D, Sloan J, Montori V, Noon A, Dabrh AMA, Murad MH. Patient engagement in research: a systematic review. *BMC Health Services Research* 2014; 14: 89. http://www.biomedcentral.com/1472-6963/14/89.

Patients' medicines management after hospital discharge – a social network analysis

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Patients are at heightened risk of harm from their medicines when their care is transferred between providers, often because of poor information sharing and limited opportunities to discuss managing their medicines with healthcare professionals [1]. Patients may have a range of medicines contacts influencing how their discharge medicines are used. Using a social networks theoretical framework, this research aims to describe the structure of patients' personal and professional medicines networks after they are discharged from hospital. It also aims to understand the functions provided by those networks.

The study was conducted with patients discharged from the cardiology wards of two acute hospital trusts. A quota sample of 60 patients was constructed based on a range of demographic variables: age, gender, deprivation and ethnicity. Semi-structured interviews were conducted six weeks after hospital discharge. The timing of the interview was designed to allow patients to interact with healthcare professionals about their medicines and to order new supplies. The topic guide was informed by a literature review and was critically assessed by a patient representative. Interviews were conducted between January and June 2014. Transcribed interview data were analysed by one researcher using thematic analysis; text was coded and codes were grouped together into themes describing the structure and function of patients' networks, and the content (what flows between network members) within them. NHS Research Ethics committee approval was granted.

Participants' ages ranged from 35–80; 42 were male and 18 were female and 9 were from ethnic minorities. Patients were from areas of high, medium and low deprivation. Patients had between 1 and 15 individual medicines contacts in their networks. Four types of contact were identified: healthcare professionals; healthcare support staff; personal contacts; and personal healthcare contacts. Some patients did not report GPs and community pharmacists to be members of their medicines networks and others experienced isolation after they left hospital. Content in the network included information and advice, and attitudes and shared experiences about medicines. Patients' networks were multifunctional: they provided practical and emotional support with medicines; provided, adjusted and monitored medicines; and offered education about medicines. Healthcare professionals performed duplicate functions and some patients experienced safety incidents as a function of their networks, for example they failed to receive new or changed medicines from their GP after their discharge. Some patients had limited views of the care each professional should provide, for example education and review by community pharmacy. Patients perceived limited contact between members of their medicines networks.

Other research has shown that patients' experiences of care transition can be disorientating [2]. We found that patients' networks included professionals and personal contacts supporting patients in their use of medicines after their discharge from hospital. While some benefit from practical and emotional support in the home, others experience limited personal support after leaving hospital. Organisation of services meant that functions – such as educating patients – were duplicated, yet patients' networks sometimes failed to safely optimise their medicines. Patients often do not experience care from professionals, such as GPs, in the way they expect.

1. The Care Quality Commission. *Managing Patients' Medicines after Discharge from Hospital*. London: The Care Quality Commission, 2009. CQC-039-500-ESP-102009.
2. Knight D, Thompson D, Mathie E, Dickinson A. 'Seamless care? Just a list would have helped!' Older people and their carer's experiences of support with medication on discharge home from hospital. *Health Expect* 2013; 16(3): 277–291.

and service evaluations (mandatory research) were the main research types undertaken. Engagement with clinical trials, applied health or clinical research was greater with HPs than CPs (85.7% versus 33.3%). Barriers to undertaking research were time (most common), lack of training, lack of infrastructure and support. The biggest incentive for research engagement was remuneration (76% (n = 39)) and time (85% (n = 12)) by CPs and HPs, respectively. CPs' potential research roles included raising public awareness (most common; 40%), recruiting patients or providing support. In contrast, HPs saw a role in leading and generating research and applying for funding. The interviews highlighted that 5 out of the 8 CPs were not aware of the Research Ready tools and their potential involvement in research.

HPs and CPs recognise the importance of research to their practice, but many are not aware of the push for involvement in research, or how they could go about doing this. Considerations for time, remuneration, training and support need to be made in order for CPs, in particular, to be more actively involved.

0004
Information required by community pharmacists to complete a Discharge Medicine Review for patients when they are discharged from hospital

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Focal points

- Aim: To identify the information required by a community pharmacist undertaking a Discharge Medicine Review (DMR) for a patient recently discharged from hospital
- A 53.7% response rate (out of 709 registered pharmacies in Wales); results can be generalised to the whole of Wales
- Results indicate a need for improved access for community pharmacists to patient information after hospital discharge

Introduction

In Wales a DMR[1] service has been established where community pharmacists review a patient's medicines on discharge, and see if there are any discrepancies between the medicines prescribed on discharge and the next prescription from the GP. There has been some debate about whether the patient's Discharge Advice Letter (DAL) should be provided to community pharmacists. The NHS Wales Informatics Service (NWIS) were keen to identify whether all or some information on a DAL is required. The aim of this project was to identify the essential information pharmacists require to complete a DMR for a recently discharged patient.

Methods

A questionnaire was developed using the Royal Pharmaceutical Society (RPS) and Royal College of Physicians (RCP) guidance on the content of DALs, including information on demographics, diagnosis, allergies, medicines, and investigations. Open questions explored other information requirements and examples of where lack of information has put patients at risk. Following pilot for content and time taken to complete, a copy was sent to all 709 registered pharmacies in Wales, along with a cover letter and a pre-paid envelope; the questionnaires were numbered to allow identification of non-respondents for follow-up. All results were transferred to Bristol Online Survey (BoS); descriptive analysis was implemented to see if there were any links between responses, and comments in open questions were thematically analysed. The project was granted approval by a university ethics committee.

Results

A 53.7% response rate was achieved, therefore no reminders were sent. Two hundred sixty-nine participants stated that they want to receive a copy of the DAL on discharge from hospital. Forty-five per cent wanted this in an electronic form and 41% by fax; 74.3% required this information within 48 hours of discharge, while 18% perceived that 48–72 hours is a reasonable amount of time. Patient and GP details, medication and medication changes, and person completing the record were deemed as essential information to be included in a DAL, whereas other contacts, diagnosis, allergies, medication recommendations, and information given to the patient and/or authorised representative were considered desirable. Thematic analysis revealed patient eligibility and service awareness as key additional areas required. Patient risk was highlighted in medicine-related incidents mainly linked to lack of communication, lack of documentation of medication information, and patients who used multi-compartment compliance aids (MCA). Cross tabulation did not imply any relation between working environment or personal details and responses.

Discussion

This study achieved its aim of exploring information community pharmacists require in a DAL. A high response rate was achieved, therefore results can be generalised to the whole of Wales. Participants' views reinforce the recommendations by RPS and RCP for the essential content of information in DALs, highlight the desire and need for access to the patient's DAL, how that should be delivered and in what time frame. Results propose further information which is deemed essential to be included and communicated to community pharmacists, and identified patient groups (those using MCAs) that require increased notification of discharge and information to allow for improved patient safety and continuity of care. More significantly, this work presents examples of how lack of information and communication may lead to patient harm and can be used to support the case for allowing access for community pharmacists to patients' health care records.

Reference

1. Community Pharmacy Wales (CPW) (2011). *Details of the DMR Service* [Online]. http://www.cpwales.org.uk/Contractors-Area/Pharmacy-Contact—Services/Advanced-Services/20111111-Details-of-the-DMR-service.aspx.

0005
Missed opportunities: the role of community pharmacy after discharge from cardiology wards

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Focal points

- This research aims to develop a better understanding of how cardiology patients experience the care provided by community pharmacy after discharge from hospital.
- Contact with community pharmacists is infrequent and can be via a proxy. Patients' experiences of community phar-

macy care are limited and many patients have unmet medicines use support needs.
- Community pharmacy misses opportunities to support patients in their medicines use after hospital discharge.

Introduction

Recent policy has attempted to position community pharmacy in a meaningful role in supporting patients' medicines use once their care is transferred from hospital to primary care[1]. This research aims to develop a better understanding of how patients experience the care provided by community pharmacy after discharge from hospital.

Methods

Semi-structured interviews with cardiology patients (n = 38) 6 weeks after hospital discharge from two NHS Trusts in England explored patient experiences of community pharmacy in supporting their medicines use. Participants were recruited by BF in hospital on the day of their discharge and selected using preselected quota sampling criteria including age, gender and deprivation and number of medicines. Their informed consent was obtained. Interviews lasted up to 1 hour, were audio recorded and transcribed verbatim. Data were analysed thematically. NHS ethics committee approval was granted.

Results

Participants' ages ranged from 35 to 80; 24 were male and 14 were female. They lived in areas of high (18), medium (13) and low (7) deprivation and eight participants were from ethnic minorities. Three main themes were identified in the data: role clarity; missed opportunities; and unmet needs. **Role clarity:** Patients' views of community pharmacy's role in their care were mostly limited to providing medicines and ensuring medicines safety. Most patients lacked awareness of the potential role of the community pharmacist in supporting their medicines use after discharge from hospital. Patients valued their community pharmacist either because they perceive a long-standing relationship or because the pharmacist provides efficient access to medicines. **Missed opportunities:** Only one patient had experienced a post-discharge Medicines Use Review and no others had been offered this service. Patients perceived community pharmacists to be medicines experts, but most explained they had not discussed their medicines with a community pharmacist. They chose instead to do so with other healthcare professionals – who they perceived to have a superior role in their care or who had allocated time to them – or leave their questions unanswered. Contact with community pharmacists was infrequent and often via a proxy (a relative, a delivery driver or a counter assistant). **Unmet needs:** Patients varied in their knowledge of what their discharge medicines are for and some held mistaken beliefs about their purpose. Others had concerns about their medicines and in some cases had stopped taking them. Some patients lacked the ability to assess how effective their medicines are for them and were unsure how their health would be affected if they stopped their medicines. Patients were unaware of how their medicines work together to help their health condition.

Discussion

Community pharmacy currently misses opportunities to optimise patients' medicines use after discharge from hospital. While most patients have some contact either in person or via a proxy with community pharmacy, many patients have unmet medicines use support needs and their perception of the pharmacists' role in their health condition management is limited. Other research has shown that transfer of discharge medicines information from hospital to community pharmacy is inconsistent in both quality and quantity, limiting community pharmacy involvement after discharge[2]. Many patients do not experience the community pharmacy medicines management service as intended.

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1. Pharmaceutical Services Negotiating Committee/NHS Employers (2013). *Guidance on the Medicines Use Review Service*. http://www.nhsemployers.org/SiteCollectionDocuments/MUR%20guidance%20final.pdf (accessed 08 April 2014).
2. Urban R, Paloumpi E, Rana N, Morgan, J. Communicating medication changes to community pharmacy post-discharge: the good, the bad, and the improvements. *J. Int J Clin Pharm.* 2013 Oct; 35: 813–820.

0006
Are sufficient efforts being made by hospital pharmacy teams to encourage patients to access a Medicines Use Review after discharge?

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Focal points

- The study investigated the relationship between hospital pharmacy referral activity and provision of discharge Medicines Use Reviews (dMURs) by community pharmacists 2 years after the dMUR service was commissioned.
- Hospital pharmacy referral activity was minimal in 50% of trusts contacted and absent in the remainder, while over 50% of community pharmacists contacted had never undertaken a dMUR, citing not knowing a patient had been discharged as the key barrier to service provision.
- It appears hospital pharmacy teams could do more to encourage discharged patients to access the dMUR service, in particular, by reminding them to tell their community pharmacist they had recently been in hospital.

Introduction

Medication errors can occur on transfer of care.[1] dMURs were commissioned in 2011 to enable community pharmacists to support recently discharged patients by ensuring no unintentional changes in treatment had occurred, provide medicines information and encourage adherence.[2] At the time, hospital

students (n = 80, 60%). Only 4 academics (19%) agreed, preferring to use the University Virtual Learning Environment, with one academic stating *'I much prefer using the University's supported platforms . . . feels more professional.'*

Discussion

The results suggest that social media could potentially be introduced to pharmacy education, and microblogging may be useful for summing up key points and asking questions. Students considered a Facebook® page regulated by academics may be beneficial for answering questions, but effects of group size and the concern that social media is considered 'unprofessional' by some academics needs to be addressed. Limitations of this project include the low response rate to the survey and that this was conducted in one School of Pharmacy.

References

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2. Safdar A. Opinion – Don't be scared to use social media professionally. *Clin Pharm*. 2015;7(2):26

0046
The burden of brokerage: patients at the centre of their medicines management networks after hospital discharge

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Focal points

- This research aimed to develop a better understanding of how patients experience medicines management services after hospital discharge using Social Network Analysis.
- Patients perceived their medicines networks (their professional and personal medicines contacts) to be poorly connected and they perceived themselves as connecting up their own networks.
- Many patients perceived a burden in organising medicines management services.

Introduction

Patients are at heightened risk from their medicines at care transfers and there is evidence that patients perceive a lack of co-ordination between their healthcare providers after they have been discharged from hospital.[1] This research aimed to understand how patients experience the organisation of medicines management services after hospital discharge and the roles that others play in managing their medicines.

Methods

A mixed-methods Social Network Analysis of interviews with cardiology patients (n = 60) approximately six weeks after hospital discharge from two NHS Trusts in England explored patients' perceptions of their personal and professional medicines interactions. A series of name generator questions and associated probes and prompts were used to identify those playing medicines management roles and explore patients' perceptions of contact between those people. A hierarchical network mapping tool was used during interviews to map patients 'networks' (the set of people with a medicines management role) and the value of each person to patients. Interviews lasted up to one hour, were audio recorded and transcribed verbatim. Patients' networks were constructed and measures were calculated to determine the extent to which the patient acted as a broker – or a go-between – between others in their networks. The number of weak network components (the number of sets of unconnected people) were also measured. Qualitative interview data were analysed thematically. NHS ethics committee approval was granted.

Results

Overall, patients recorded a mean network of 6.44 (SD 2.71) professional and personal network contacts. A quarter of the sample (15) perceived no connections between any of those network members. On average women perceived slightly denser (more connected) networks than men. The mean number of ties between network members was 5.28 (SD 9.26). Patients' networks had a mean normalised brokerage calculation of 0.88 (SD 0.15), indicting they largely perceived themselves in a 'go-between' role. On average there were 4.48 (SD 1.64) weak components (unconnected sets of people) in each patients' ego network; 74.7% (SD 20.6) of patients' ego networks comprised weak components. In interviews most patients reported perceiving low levels of contact between professionals in their networks. Some made distinctions between sharing information electronically and active spoken and/or written communication about them and their health. Patients perceived cardiac rehabilitation nurses to actively communicate with others, such as hospital doctors and GPs. Some patients described frustration at the lack of continuity in their care team. They particularly perceived poor continuity in their contact with a GP. These patients perceived a burden in updating their healthcare professional network members about their health condition and treatment.

Discussion

Overall, patients described very loosely connected networks and perceived themselves as playing a strong broker role linking their medicines management network members. Other research has described patients and HCPs experiencing poor care continuity after hospital discharge.[2] That patients perceive a lack of connectivity amongst members of their medicines networks once they have left hospital may add to the burden they experience in managing their treatment and their health condition.

References

1. Knight A D, Thompson D, Mathie E, Dickinson A. "Seamless care? Just a list would have helped!" Older people and their carer's experiences of support with medication on discharge home from hospital. *Heal Expect* 2013;16(3):277–91.
2. Stafford L, Van Tienen E, Peterson, G M et al. Warfarin management after discharge from hospital: A qualitative analysis. *J Clin Pharm Ther* 2012;37:410–14.

Patients attended monthly assessment clinics where pain scores were routinely recorded in medical notes. Ethics and governance approvals were obtained to collect data from the notes of consecutive consenting patients (n = 25) being treated with topical gabapentin for refractory, focal peripheral neuropathic pain. A clinically significant reduction in pain score was deemed to be 2^2. The case mix included post herpetic neuralgia (PHN), painful diabetic peripheral neuropathy (PDPN), chronic post surgical pain (CPSP), complex regional pain syndrome (CRPS) and vulvodynia. Patient